

## Jon Shaw Foundation — charity number 1189073

## March 2024 Newsletter

## **New Recipients**

Since our December newsletter, we have donated 32 monitors. We have also donated 13 safety pillows to young people living with epilepsy. We have been able to organise and fund bereavement counselling sessions for a group of primary school children, after they lost one of their classmates suddenly last year. 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. Here are just a few.



This is Aaron, his seizures are nocturnal, his parents feel like they haven't slept since his first seizure in 2020, always on high alert, scared to go to bed. They have found Aaron blue and unresponsive on many occasions and hopeful the SAMi will be a life-saver. We are extremely grateful to Jon Shaw Foundation. It means so much to us as parents to finally have peace of mind.

This is Mabel who was diagnosed with Myonclonic Epilepsy at 9 weeks old. Her mum had been struggling with sleep since the diagnosis. She told us that the SAMi camera we funded is a life-changing for them, it monitors Mabel when she is sleeping and records seizures so that they can show them to the neurologist. "I am forever grateful and will be fundraising for JSF"





Jon Shaw Foundation

Headlines

**New Recipients** 

**Recruiting Trustess** 

**Fundraising reports** 

Support Group

Thank you

A 2 year old Jon, who badly injured his hands

### Inside this issue:

Message from the Founder	2
Recruiting Trustees	2
Epilepsy Support Group	2
Fundraising Events	3
Thank you to businesses for their continued sup- port.	4



Getting the epilepsy diagnosis wasn't the scary part for mum, it was when her daughter started medication and the seizures kept coming day and night. With the SAMi 3, mum knows she will be alerted when a seizure happens which gives her the chance to sleep and

know she can get to her when she needs me. "Thank you Jon Shaw foundation."

Mum told us "I want to thank the Jon Shaw foundation, They helped towards the cost of a SAMI camera for my son. We have been using the camera for a week now, I'm still adjusting the settings but feel less anxious about leaving the room while my son sleeps, I have even slept in my own bed a couple of times!! Thank you for all your help. I am so grateful x"



#### ► Page 2

#### March 2024 Newsletter

## Message from Wendy Shaw—Founder of Jon Shaw Foundation

First of all Happy new year to everyone, I hope you are well and staying safe. We have landed into 2024 running with lots of applications for equipment. I think we have caught up with them all now and hope that those we couldn't help at this time understand our reasons and those we could help are finding the equipment is having an impact. I think it is wonderful that a number of our families are helping other families in need of our support by arranging fundraising events for Jon Shaw Foundation. We have to rely on the goodness and generosity of people and businesses to keep us running and we are always so grateful for the support in these most difficult times. We know that people are struggling but still they find a way to give. We couldn't help change lives without you all so thank you. Sadly we weren't successful in our bid to be the Headline Charity for the Krazy Races Event in Crewe but fear not, we will keep trying other avenues, thank you for taking time to vote anyway. As you know March is a difficult month for our family as it would be Jons 24th birthday on 22nd. We celebrate his life privately but have also dedicated the date to the work we do in his memory. So 22 March is Jon Shaw Foundation Awareness day (Unofficial, if I could afford to make it official I would). Then a few days later it is Epilepsy Awareness day (Purple Day). A few of our families are marking the day by wearing purple and raising funds for us. Why not join us all by wearing something purple on 22 and 26 March. I look forward to seeing you at our fundraising events throughout the year and hearing about how our work has helped you.

Thank you

Wendy Ghaw



## Two trustees needed to join our team.

Sadly two of our lovely trustees have had to step down recently so we are looking for two people who want to help us make a difference. The two trustees will have specific roles, both vital to the lawful and safe governance of the charity. You will need to commit to four meetings per year, including our AGM and help make decisions on funding requests. All training will be provided and our volunteer coordinator will ensure that you are aware of your role and responsibilities.

If you would like to be a part of our team, please contact us on

enquiries@jonshawfoundation.org



# Support Group for Families living with Epilepsy - W. Yorkshire

Our Support Group for families living with epilepsy had its second outing on 16 February, Lauren finally found an alternative venue as the previous one was no longer available. She and Diana greeted families who were able to chat over tea and biscuits and share experiences. Managing a condition like epilepsy can sometimes make parents feel isolated so getting together with others who understand is really important and supports mental health among families. Lauren has kindly agreed to continue running the support group, if you would like to attend the next meeting, keep an eye

## Robina has been baking again.



Yes, our resident baker has been at it again, she held a cake sale and tombola last month, and raised a fabulous £661. 40. She and her family did all the baking and gathering of goodies for the tombola to raise money to help us raise awareness of SUDEP and for an orphanage in Rwanda . What a superstar she is, the amount of work involved in putting this together single-handedly is huge. What an amazing thing to do. On behalf of all the young people your contribution will help, we thank you.



## Going Purple for Jon Shaw Foundation

22nd and 26th March are significant days in our calendar, Jon Shaw Foundation Awareness day and Epilepsy Awareness Day. At least three of our families are supporting us by wearing purple. Two families have involved school and encouraged everyone to wear something purple and the other is taking part in the Aintree 5k Inflatable run. Sounds like fun. Good luck to both families and thank you so much for your support. If you would like a T Shirt we have a few adult and children sizes left at £10 each. Thank you to Chris Cornes of Anything on T Shirts for printing the shirts.

# Darts Tournament at Cheshire Cheese, Middlewich



A big thank you to Kieran Wilkinson for organising this Charity Darts Day, Kieran and his family have given us a lot of support since we first met them . The teams are full now but if you can support the event by attending and cheering them on or you can donate on their just giving page, www.justgiving.com/page/cheshire-cheese-darts

Thank you to the Cheshire Cheese for providing the venue. Kick off 1pm!



## Easter Hamper Raffle

We are holding an Easter Hamper raffle again this year. We have 2 x hampers and at least 2 other prizes. Thank you to the trustees and to Roz one of our associate members who have all donated eggs. Thank you also to Morrisons, Dunwoody Way who have also donated a prize. Thank you to Jackie at the White Lion Crewe, for displaying our hamper and selling our tickets.

Tickets are 50 pence each and are available from our facebook page or from the White Lion Pub, Warmingham Road Crewe.

The winners will be drawn at the White Lion on 26 March (Purple day)



## Thank you to these businesses for their continued

## and vital support

As a small charity, we could not succeed without this help. We can always rely on a number of organisations for advice, moral support, provision of essential materials for the smooth running of the Foundation and donations for our fundraising events.

### **MITCHELL PLANT REPAIRS**

#### www.plant-repairs.co.uk

Nick has very generously supported us in many ways since we registered

### The White Lion Pub

### www.thewhitelion.biz/crewe

Jackie has supported us with fundraising since we registered

## We-Display

#### www.we-display.co.uk

Mark, Michelle and team have supported us from our first days, building our website and helping with our stationary.

### **CARTRIDGE PEOPLE**

#### www.cartridgepeople.com

Cartridge People have provided all the ink we need for produce all our stationary and communications.

### YouSpa SANDBACH

#### www.you-spa.co.uk

Michelle and her team, have supported our fundraising events, filling tables and providing wonderful prizes

## Arriva TrainCare

#### www.arrivatc.com

Crewe Depot have provided fabulous prizes for our fundraising events

### JON SHAW FOUNDATION

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#### <u>https://</u>

www.easyfundraising .org.uk/causes/ jonshawfoundation/? utm\_campaign=raise



https://www.onelottery.co.uk/ support/jon-shaw-foundation



Scan the QR Code to go to our Just Giving Page to support the individual fundraising events