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Welcome to issue #10, we hope you enjoy reading these regular updates - keeping the AngelmanUK community connected.

If you require information or support please email <a href="mailto:support@angelmanuk.org">support@angelmanuk.org</a> or click on our logo which takes you to our website.

# join us

Are you the person AngelmanUK is looking for?

AngelmanUK is evolving and we are looking for new people to join our team of trustees and regional representatives. This will be a voluntary role but reasonable expenses will be covered. Trustees will be expected to attend 4 'in person' trustee meetings during the year and other on line meetings where necessary. Community ambassadors will be invited to attend meetings but are under no obligation to attend in person.

Do you have a specialist or professional interest in:
- Communication

- Health & welfare
- Science & research
  - Governance
  - Fundraising
- Marketing & social media
- Community engagement
  - Event planning

#### Do you live in

- Scotland
- Northern Ireland
- another region under represented by AngelmanUK

Would you like to know more about what is involved?

Please contact <a href="mailto:info@angelmanuk.org">info@angelmanuk.org</a> with your preferred role in the subject line and we'll get back to you as soon as we can.

### christmas

We have a brand new selection of Christmas cards available to purchase in support of AngelmanUK. The cards have been designed by our families and we are excited to share that you can purchase them as traditional paper cards or as an E card and donation to AngelmanUK. Please follow the buttons below to make your purchase.

Paper cards

E-cards

# family

Jasmine (AS del+) lives at home in the Worcester area with her dad, Dan (AUK trustee), mum, Cherry, and younger brother, Max (4).

#### What are her likes & dislikes?

Jasmine loves people, water, her swing, being out and about and partying! We're often out in our camper going camping and to festivals etc. and Jasmine has become very popular. She especially loves the lights and the people at the bigger events where she has a plentiful supply of people to entertain her. She dislikes waiting for food if she's hungry and being kept indoors for too long.

#### Can you name one of her most recent achievements?

It's slow progress mostly with her walking improving over time and she is now able to stand still for quite a while if she wants to.

Just today I was surprised though. Her brother has a fever and was laying down and she went over to him three times and stroked his hair and gave him a kiss. I was expecting her to pull his hair but she didn't and I'm fairly convinced this was genuine affection. I'm certainly giving her the benefit of any doubt.

#### Is there anything you'd like to share with our families?

So many things but I will try to keep it short. Firstly I would suggest that people engage in the AS community and attend events if they can. There is so much experience and support available from other families and some great friendships are made within the community with people who just completely understand the challenges and ups and downs of AS.

The other thing I would like to say is to do your best to enjoy life wherever possible. Everyone in this community has challenges, some moreso than others, but I can't remember a time when I have regretted getting out and about with the family (perhaps I have a poor memory but it is definitely mostly positive). Not when in a rainy, muddy campsite/festival field. Not when dragging a terrible NHS wheelchair across the beach (something I hope to resolve). Not when more of the food in a restaurant ends up on the floor than in her belly. It can be hard work but it's all worth it so that we can all have a good time and it is really important that we all have those fun times. The camper works really well for us because Jasmine is really difficult to settle in unfamiliar places like a hotel but wherever we take it, the camper is home and she settles better there than anywhere.

We're looking forward to visiting family in Thailand over Christmas for the first time in four years. The flights are another one of those things that aren't fun but very much worth the effort.

We really look forward to meeting more of you at next years family conference.



# shop

We're ready for the festive season, you can find our range of Christmas sweatshirts and t-shirts online now by clicking the button below.



Shop now

# thank you

Without your fundraising and your donations there would be no AngelmanUK to offer support to your family. Whether big or small, every penny really does make a difference. Don't forget to keep up to date with us on social media to see who has raised money for us recently. If you have images to share with us, please email them to **fundraising@angelmanuk.org** 

You might have seen us talk on social media about Team AngelmanUK, our group to bring together those who take part in sport fundraisers and celebrate their achievements. If you'd like to be part of Team AngelmanUK or are

#### interested in being an ambassador for us, please email team@angelmanuk.org

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