

Welcome to issue #3. We hope you enjoy reading these regular updates - keeping the AngelmanUK community connected.

If you require information or support please email <u>support@angelmanuk.org</u> or click on our logo which takes you to our website.

AngelmanUK is 30!

30 years of supporting and educating families and professionals about Angelman Syndrome. What an amazing thing those pioneering parents who got together in the early 90s started, and what a journey it's been!

Please join us in celebrating this legacy by hosting a Big Birthday Brunch or a Party in the Park for your local friends and family. Order a fundraising pack via our shop and check out our Fabulous Fundraising booklet for ideas. If you're meeting in a park you can use our balloons and bunting to festoon a picnic table, and decorate cupcakes with our AngelmanUK and smiley cake toppers...the suggestions are endless. We will do all we can to support and publicise your event so please let us know the details by emailing <u>fundraising@angelmanuk.org</u>



Booking open!

Communication Conference – Fri 27 -Sun 29 Oct 2023

We have BIG NEWS! We are very honoured that Karen Erickson, Ph.D., will be joining us for the event and will present the keynote speech to professionals on Friday 27. Dr Erickson welcomes the contribution of attending families to her research project into Cortical Vision Impairment.

Book here

family

Hannah is 37, she lives with her mum, Gill and dad, Dave, in Brantham, Suffolk. She has a younger brother (36) and older sister (38) who she is very close to.

What are her likes & dislikes?

Hannah is very active and is always keen to go out. She loves walking her dogs, horse riding and swimming. She also enjoys going to her day centre which has an allotment, animals and various outings including respite trips with her friends to the day centre's caravan. She goes to stay with her sister on alternate weekends, as soon as her sister arrives to pick her up she is out of the door! Hannah's behaviour can be challenging so we plan outings to avoid this. She loves her bedroom, and doesn't like us sitting on her bed as it is her space.

Can you name one of her most recent achievements?

Her greatest achievement recently was to take her dog for a walk. Although we have four dogs, Fenn is hers, Fenn has never been trained in the role, she will lay with Hannah if she senses that Hannah is upset, ill or having a seizure, they are so close.

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

Hannah lives life to the full, family is very important to her. She loves family gatherings, eating out and having a laugh. Life can be hard and tiring but Hannah brings a lot of happiness. Everyone in our village knows her and she loves going out and greeting everyone with a cheery "Hello".

If you'd like to be one of our featured families, contact sian.allen@angelmanuk.org





Fundraising packs

Our Fabulous Fundraising pack is now available. Inside the new pack you will find a little yellow book of Fabulous Fundraising ideas as well as a selection of items to help make your fundraising activity a huge success.

Be sure to send an update and any photographs of your event to share on our socials to sian.allen@angelmanuk.org

Order here

ASF family fund

We are very happy to announce that the ASF/AngelmanUK family fund is now open for applications.

AngelmanUK will contribute up to £500 towards items such as an iPad and/or communication app, an adaptive trike, a travel bed or other items which enhance the life of your loved one with AS.

Applications open to people of all ages including adults with Angelman Syndrome, if registered with AngelmanUK. Follow the link to the ASF website to apply.

https://www.angelman.org/family-fund-application/

AS clinic

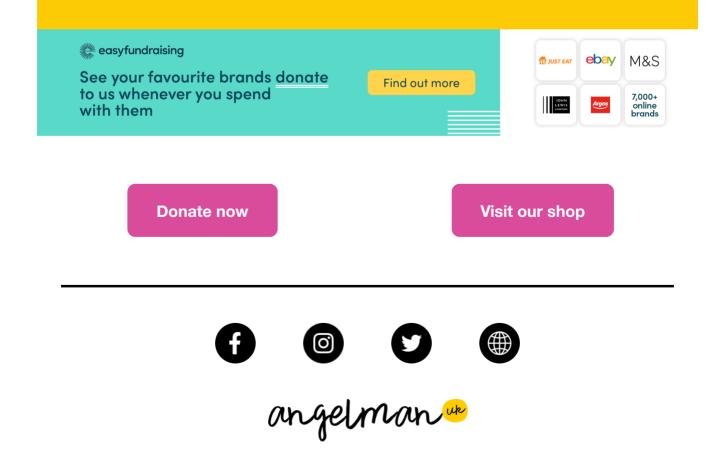
The Angelman Clinic in Manchester is now open to referrals for people of all ages with Angelman Syndrome. If you would like to see a team of specialists who can you help navigate any medical issues relating to Angelman Syndrome, please ask your GP, Paediatrician or Consultant to refer you to

Dr Catherine Breen Consultant Clinical Genetics Manchester Centre for Geonomic Medicine St Mary's Hospital Oxford Road Manchester M13 9WL

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 <u>fundraising@angelmanuk.org</u>

We are now actively promoting 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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