



Welcome to issue #8, 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.

## thanks

Thank you to everyone who has attended our picnics over the last few weeks, we've had a fantastic time catching up and getting to know you all! We hope you all had fun.

Thank you to our fantastic hosts who volunteered their time at the weekend and brought our families together, we couldn't have done it without you all.

### research

Opportunity for parents starting soon.

A Master's student at Cardiff University is looking to recruit parents or legal guardians for one-off interviews which will be online and audio only.

### You are eligible if you:

- Have a child (of any age) with Angelman Syndrome- Are over 18 years old

#### Topic of research

Exploring the impact of having a child with Angelman Syndrome

For more information, or to register interest, please contact the researcher Ella Kershaw at **KershawER1@cardiff.ac.uk** 

## family

Anna is 18 years old and lives near Poole in Dorset. At the moment she is still living at home with her family but will soon be transitioning into supported living. She continues to attend a local specialist school.

#### What are her likes & dislikes?

Anna is very sociable and enjoys being around people. She loves to visit the farm and interact with the animals, trips to the supermarket and local park. She enjoys swimming, bowling and pop music, Abba being a favourite! At home she likes to relax with her iPad watching YouTube videos.

Anna doesn't like waiting for dinner, her hair being brushed, getting out of the bath and is not keen on Marmite!

Can you name one of her most recent achievements?

Anna recently attended her school prom and looked amazing in her prom

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

I'd say to any family never underestimate the capabilities of these kids.

Despite her difficulties, Anna continues to surprise me every day with her understanding of the world around her. She is a remarkable young lady who never forgets a face, tries her utmost to please and after a pinch or a hair pull, a hug is never far behind.

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



## clinic

Don't forget that you can request a referral to the Angelman Clinic in Manchester via your medical team. The next clinics will be held in September 2023 and March 2024.

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

More info

# 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 <a href="mailto:fundraising@angelmanuk.org">fundraising@angelmanuk.org</a>

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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