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Welcome to issue #6, we hope you enjoy reading these regular updates -
keeping the AngelmanUK community connected.

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

feedback

We want to support you in the best way possible, so we are seeking feedback
from the Angelman Syndrome community. Please click the button below to
complete our survey.

[Take the survey](#)

siblings

Congratulations to Arthur on receiving an Inspirational Young Person award for the support he gives to his younger brother, Bertie, who has Angelman Syndrome. We'd like to thank him for helping to raise awareness, and money, which is incredibly important for our community.



research

“Roche has made the difficult decision not to move forward with a new clinical trial for rugonersen and has initiated the search for an external partner to take over the development. The conclusion of this trial undoubtedly brings feelings of disappointment, frustration, and sadness for many of us who have hoped and advocated for a breakthrough in the treatment of Angelman syndrome. It is a disappointment we share, and in this moment, it is crucial that we come together as a community to support one another. First and foremost, to those brave families that participated in the trial and made so many sacrifices for this community, we are in debt to you and your amazing individual with AS.

The primary objective of the ongoing Phase 1 TANGELO study is to evaluate the safety and tolerability of rugonersen. During the interim analysis (looking at the data at a pre-planned point while the study is still ongoing) rugonersen has demonstrated an acceptable safety profile. Although some encouraging effects were observed in the patients’ EEG, the level of clinical improvements in the TANGELO dosing regimens and as compared to natural history data (the usual course of development of individuals with AS in the absence of treatment) did not meet Roche’s internal criteria to move into the next phase of clinical development. They will still be moving forward with their alogabat trial and we will continue to partner with them to get this to the finish line. This setback does not diminish the incredible progress we have made together, nor should it diminish the hope for possible treatments in the future. This landscape can be very hard to navigate, but there are still so many promising trials in process and in the pipeline that should give this community so much hope.” ~ Angelman Syndrome Foundation

[Read more](#)

family

Ruby is 7 years old and lives in Hertfordshire with mum, Felicity, dad, Dean, and younger siblings Lily (5), Tobias (3), and Lucy (1).

What are her likes & dislikes?

Ruby loves giving special cuddles, especially to the men in her life! She loves being with her family, dancing, listening to music, looking at photos, swimming and reading books. Ruby enjoys breaks and holidays with her family - Center Parcs, Butlins and abroad! She also loves going to the cinema, bowling and making (and eating!) cakes. Ruby is very empathetic and the centre of our family. Ruby's biggest dislike is having her teeth brushed! She also dislikes animals and has become fearful of some of them.

Can you name one of her most recent achievements?

We are proud of Ruby for so many reasons! She has already exceeded what we could have hoped for her! Ruby is toilet training and is now able to tell us when she needs the toilet by tapping her body, tapping the toilet door or standing by her toilet. Ruby is also beginning to use her iPad with purpose in daily life to let us know what she would like to eat, which book she wants to read and has learnt to say 'night night' to her family, tell family that she loves them and request a cuddle or a kiss.

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

We treat Ruby the same as her siblings and we allow her to participate in life at the same level as them. Don't ever put a limit on what our little ones can achieve! Always assume competence and believe in them! They really can achieve so much if we give them the tools to do so.

If you'd like to be one of our featured families, contact

sian.allen@angelmanuk.org



We are pleased to announce that we have partnered with Run for Charity, which gives us access to over 350 local events from running, cycling, walking and even adrenaline raising challenges including bungee jumps and inflatable races. Either choose from one from the list below or select your region to find an activity near to you.

Take a look at the events we have subsidised entry for, or check out all the choices in your local region. We look forward to seeing what you choose!

[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 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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