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hello

angelman^{uk}
support education research

Welcome to issue #4, 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.

30th birthday

Can you help us celebrate our 30th birthday?

Could you host a 'Party in the Park' in summer with local AS families, or
perhaps a 'Big Birthday Brunch'?

How about holding a cocktail and canapés evening for adults? You could
We can supply you with balloons, bunting, cake toppers & flags to make your
event a success whatever you decide to do!

Please let us know if you can help us celebrate and we will contact your
families local to you so all you need to do is turn up and have fun! We'll even
send you a free birthday T-shirt as a thank you!

research

Exciting updates from one of our recent [ASA - Angelman Syndrome Alliance](#) funded grants!

Truly exciting and cutting-edge research for Angelman Syndrome! The goals of this Angelman Syndrome Alliance - funded grant are to improve future AS therapeutic pipelines by working on a less invasive method to deliver antisense oligonucleotides (ASOs) to the brain.

The proposed brain-delivery strategy for ASOs targeting Ube3a, will be based on biocompatible nanoparticles that can be delivered non-invasively via intranasal (using a nasal spray) administration and to assess non-invasive imaging methods as an unbiased biomarker for monitoring brain function in Angelman Syndrome.

Click the link below to learn more about this work.

You can find more information about Angelman Research in the Angelman Research & Trials group on Facebook.

[More info](#)

family

This is Maeve, who has just turned 2. She lives at home with mom (Emma) and dad (Luke), who are both teachers.

What are her likes & dislikes?

Maeve loves all things to do with motion! Spinning round in dad's arms and swinging in a blanket are her favourite things to do. She also loves animals, particularly dogs. As with most children with AS, Maeve adores all types of food - it was the first sign she learnt to do! She dislikes being bored, overly crowded places and when she gets too hot.

Can you name one of her most recent achievements?

Maeve's most recent achievement is one of her physiotherapy program moves which is helping her to learn to sit independently. She now uses her tummy muscles to sit up when we push her flat onto her crossed-legs. She will now look up and bring herself back up into supported sitting. This is a massive achievement and we are working on weight-bearing through her arms too.

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

Our message to other parents would be thank you! The AngelmanUK family has proven to be so important to the way in which we have dealt with Maeve's diagnosis as a family. As a special needs teacher who has taught children with the condition previously, I thought that I knew all there was to know but doing it from the side of a parent is oh so different! Where we previously felt alone and confused, the other parents gave us hope and real-life experiences which made us realise that those first things you read about the condition are not definitive. To new parents, I would encourage them to reach out, ask as many questions as you need to and just know that someone out there is dealing with exactly what you are. The grief never goes away but there is so much joy to be had with our beautifully unique babies!

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

sian.allen@angelmanuk.org





sporting events

Would you like to enter a sporting event and be a part of Team AngelmanUK? We've partnered with Run for Charity to offer more opportunities for everyone to get involved, including people with Angelman Syndrome and their siblings. Find out more and join Team AngelmanUK on Facebook for updates.

zoo trips

Thank you once again to everyone who helped to make the Easter zoo trips a success. It was wonderful to see lots of you in person again, we hope you all enjoyed meeting up with each other!

marathon

Thank you to everyone who took part in this year's TCS London Marathon, and thank you to everyone who supported them by donating.

We're blown away as always by your months of dedication and determination, we hope you all enjoyed the experience and have recovered from the big day!

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

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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