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Welcome to issue #5, we hope you enjoy reading these regular updates -
keeping the AngelmanUK community connected.

If you require information or support please email [**support@angelmanuk.org**](mailto:support@angelmanuk.org)
or click on our logo which takes you to our website.

Webinar

Clinical Trial Basics: What Parents Need to Know About Trial Participation

Jennifer Panagoulas

*Head of Regulatory and Policy at
FAST, Co-director of ABOM*



THURSDAY
15 JUNE 8PM

Register Now



If you're a parent or carer interested in learning more about clinical trials, this webinar is a must-attend!

Jennifer Panagoulas, an expert in the field, will guide you through the basics of clinical trial participation and provide valuable insights for parents.

Jennifer's presentation covers the fundamentals, followed by a Q&A session where you can ask her any questions related to clinical trials.

Reserve your spot now by clicking below:

Register here

family

James is 21 and has the deletion form of AS. He lives in North Wales with his mum, Rachel, his sister Beth and brother Zac.

What are his likes & dislikes?

James enjoys socialising with friends and family and he loves his iPad. He also gives the world's best bear hugs! James is very perceptive and empathetic - he knows when people are upset and can be very gentle when he needs to be, despite his strength and size!

Can you name one of his most recent achievements?

I'm very proud of James for using his iPad as a communication device. He is still learning to use it despite having it for many years. He mainly uses it to ask for his favourite food & drink or to visit his favourite restaurants, but he has also used it to talk about future events or people he wants to see. He still manages to surprise me with his level of understanding around time and place.

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

I think it's important to remember:

1. People with Angelman Syndrome continue to learn & develop throughout their lives.
2. No one can say what your child will or won't be able to do.
3. Try not to focus too much on the future, enjoy the present and get through one day, one week, one month at a time.
4. It gets easier.

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 events including bungee jumps and inflatable races. Either choose from one of the events below or select your region to find an event near to you.

Take a look at the events we have subsidised entry for, or check out all the events 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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