News from our participants

It is fantastic to be able to share news from our participants, some of whom are now 4 years old and have started school.

We would like to congratulate Aileen and her family on the birth of her third child Ellie who was born in July this year. We are delighted to hear that Nicola is loving being a big sister!

Aileen told us why she had wanted to take part in the FADES study:

“I decided to take part in the FADES study as I believe that my daughter Nicola has a great life ahead of her and that’s because of research that has been done in the past. I fully expect Nicola to have educational achievements, hold down a job, live an independent life and have meaningful relationships. This is all possible because previously people have researched ways to make life better for people with Down’s Syndrome. The FADES study could potentially benefit Nicola when she is an adult and help her avoid some of the medical challenges that she is more likely to have. I believe it’s important to support meaningful research relating to Down Syndrome as ultimately it could benefit my daughter and others with Down Syndrome.”

World Down Syndrome Congress 2018

Attending The World Down’s Syndrome Congress in Glasgow in July was one of the highlights of 2018. We enjoyed meeting so many fantastic people, finding about the wonderful work and research that is going on in for people with DS throughout the world and hearing the inspirational stories from those with DS.

Meeting and talking to families who were already involved in the FADES Study or who wanted to talk about the potential impact that the study could have was fantastic. The FADES symposium which was presented by Dr Kathleen Gillespie, Dr Georgina Williams and Georgina Mortimer led to a great interest in the study with delegates in the audience including families, world experts, collaborators and future collaborators.

The Bristol Biomedical Research Centre (BRC) Nutrition Theme is funded by the National Institute for Health Research (NIHR) and is a partnership between University Hospitals Bristol NHS Trust and the University of Bristol.
FADES Update

We are thrilled to say that we now have 90 families enrolled in the FADES study. Children can currently remain in the study until 2022. If you have any queries about the study extension, please do get in touch.

We have also now extended recruitment until 2020 enabling even more families to be part of FADES.

As always we couldn’t do any of this without the amazing families who take part in the study we are very grateful for all you do. We also want to thank the Down’s Syndrome Association, Down’s Syndrome Scotland, the Down’s Syndrome Medical Interest Group and all of our collaborators for all their help and support.

Don’t forget to let your friends know about the FADES study, we are still looking for new families.

If you would like any further information or if you would like to feature in the next newsletter please contact us: fades-study@bristol.ac.uk

Georgina Mortimer presented a poster on the study at the Immunology of Diabetes Society Congress in London.

The conference was attended by international researchers in Type 1 Diabetes and autoimmunity. The study poster generated a wealth of interesting conversations.

A BIG THANK YOU FROM FADES

Georgina Mortimer