Happy Holidays

We hope that all the children and families taking part in the FADES study, enjoy the season’s festivities. We want to take this opportunity to thank everyone who has been involved since the study started in 2014.

**FADES extended until 2022!!!**

We are very excited to tell you that the FADES study has now been extended until 2022. We have now received further funding as the NIHR Bristol Nutrition BRU has now been expanded into the NIHR Bristol Biomedical Research Centre Nutrition Theme.

For Children currently in the study who were born before the 1st January 2017 we will be sending out a copy of the new participant information sheet and consent form to you. By parents completing the consent form, these children will be able to remain in the study beyond their fifth birthday up until 2022. We have also extended the recruitment deadline so that new families will be able to enter the study until January 2020. So please continue to spread the word about FADES.

There are now 75 families in the study with more families joining every month. Some of our children have now celebrated their third birthday and so has George Armour. George’s photo has been brightening up our flyer for the last few years. George’s family have kindly sent us a photo from his 3rd birthday. We love hearing how all your children are getting on.

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**Involving Families and Children with DS in research**

Some of you may remember that as well as the main study, we have been looking at how we might help more families get involved in research. We are trying to understand the barriers and motivations for families with a young baby with Down’s Syndrome to take part in research.

We interviewed charity support workers, community paediatricians, neonatologists and research nurses who are experienced in working with families. Some of those that we interviewed were also parents of a child with DS themselves. The interviews have been analysed and we have submitted a paper for publication. The conclusions from the analysis were that every parent may respond differently to the diagnosis of DS for their baby and that researchers need to be sensitive to this. They also need to be aware of the child’s medical needs and how this may affect the family. None of the factors revealed in interviews would preclude recruitment into research. If researchers want to encourage more
families into studies such as FADES a flexible approach is required. They need good communication skills and understanding of the dynamics that may be taking place in the first few months of life for babies with DS and their families.

We hope that this work will help to inform this study and future research in babies with Down’s Syndrome. Thank you to everyone who has took part in this.

Thank you also to all of those who previously responded to our questionnaire, which asked about why you decided to take part or not to take part in FADES. We will shortly be sending out questionnaires to those of you who have not previously had the chance to complete this, so please look out for this!!

**Introducing Sofia and Georgina**

We wanted to introduce you to Sofia, our study administrative assistant, who many of you will have received emails and reminder emails from.

Sofia has worked as the administrative assistant in the Nutrition Theme of the NIHR BRC since January 2016. Her job role within the department is to provide a wide range of administrative support, as well as liaising with staff across the Trust and University of Bristol. Prior to this, Sofia worked as an outpatient reception clerk, in a specialised department within the Diagnostics and Therapies division, which is part of the University Hospitals Bristol NHS Foundation Trust.

We also wanted to introduce Georgina Mortimer. Georgina makes up and sends out all the sampling kits, receives all the samples that you send, carefully records and stores them ready for analysis. Georgina also does some of the testing in the Lab.

After working as a Research Technician for three years with the Diabetes and Metabolism Unit, Georgina has just started a part-time PhD in Autoimmunity and Down’s Syndrome.

**A BIG THANK YOU FROM FADES**

We would like to thank all our participants and their families, the Down’s Syndrome Association, Down’s Syndrome Scotland, the Down’s Syndrome Medical Interest Group and all our collaborators: we couldn’t do it without you!

We love to hear your stories and about your baby’s progress. Please do send us photos and updates that you would like to be included in the newsletter.

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