

Genetic Medicine  
Manchester Academic Health Science Centre  
Central Manchester University Hospitals  
NHS Foundation Trust  
Saint Mary's Hospital  
Oxford Road  
Manchester M13 9WL  
Direct Line: 01617012043

25<sup>th</sup> August, 2016

Dear Parent,

Re: Early DEvelopment in Neurofibromatosis type 1 (EDEN) study

As part of the clinical team at Genetics Department, Central Manchester Hospitals, I am writing to invite you to participate in a research study involving babies with NF1.

When a baby is diagnosed with NF1, there's no way to tell exactly how his, or her, life will be affected. Some children are affected very mildly and may notice nothing more than skin changes, yet others are more severely affected. At least half of all children with NF1 experience problems with their learning, difficulties with attention and concentration. One in 4 children can be affected by Autism Spectrum Disorder (ASD) and as such find it difficult to function day-to-day in school, have trouble forming friendships and social relationships.

Our research team is searching for ways to tell, much earlier than is currently possible, whether a baby with NF1 is going to develop ADHD or ASD. If the tests we're investigating can provide an early warning that a baby with NF1 is likely to develop ADHD or ASD, they could enable earlier diagnosis and treatment. They could also make it easier to plan what sort of support babies are likely to need, both at home and at school, while they're growing up. Earlier treatment, and better support, could improve the lives of babies and their families' significantly. Tests that can reveal early signs of ADHD and ASD would also be useful when assessing the benefits of experimental treatments. Ultimately our goal is to find ways to stop babies with NF1 from developing ADHD and ASD, or lessen the severity of their symptoms.

Please find enclosed an information leaflet which tells you more about this new study. If you are interested in participating in this research please read the information sheet provided, fill in the enclosed indication of interest form and send it back in the pre-paid envelope provided in the pack. Alternately you can contact NF nurses on 0161 7012043 to find out more about the study. No details will be passed to the research team without your permission. Expressing your interest at this time will not commit you to taking part in the study if you later change your mind.

Yours sincerely,



Gareth Evans  
Professor of Medical Genetics & Cancer Epidemiology