

FACEMATCH INFORMATION

Research Project Title: The FaceMatch Project (**HREC project number:** 17/05/17/4.06)

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We would like to invite you to participate in **The FaceMatch** project.

WHAT IS THE BACKGROUND TO THE FACEMATCH PROJECT?

Parents of a child with moderate to severe developmental delay or intellectual disability (ID) often spend many years and medical appointments searching for a diagnosis. Although there are various prenatal and environmental causes, the most common cause is genetic. Genetic changes can be inherited from one or both parents, but often occur for the first time in a child. A specific diagnosis can guide medical management and reduce the sense of isolation for the family.

Improved genetic testing has made it possible to test an individual's entire genetic makeup (the genome) including all the known (approximately 1500) genes important for brain development, in a single test. However, a diagnosis is still only achieved approximately 30-50% of the time. There are a large number of genes involved in brain growth and function still to be discovered. There are also countries around the world where advanced genetic testing is unavailable.

WHAT IS THE AIM OF THE FACEMATCH PROJECT?

FaceMatch aims to work with parents to develop a large secure facial image database which can suggest a diagnosis in people where genetic testing has not provided an answer or where genetic testing is unavailable. People with the same genetic condition can often share similar facial features. Using advanced computer vision technology to match the faces of children from around the world, the project aims to provide a diagnosis for more families and to assist the discovery of new developmental genes.

WHO CAN PARTICIPATE IN THE FACEMATCH PROJECT?

- 1) Parents of children or adults with moderate to severe developmental delay or ID who have a confirmed genetic diagnosis. Contributing to the FaceMatch project will improve our image database and help other families still searching for a diagnosis.
- 2) Parents of children or adults with moderate to severe developmental delay or ID who remain without a genetic diagnosis following review by a clinical geneticist.

WHAT DOES PARTICIPATION IN THE FACEMATCH PROJECT INVOLVE?

You will be asked to provide information for your son or daughter's profile page in the secure FaceMatch platform. This will include uploading photographs of them at different ages and providing relevant medical information. (With your written consent, your doctor can do this on your behalf).

Every new image uploaded into the FaceMatch database will be matched against all other photographs within the database within milliseconds. Photographs identified as very similar will be reviewed by the FaceMatch team and doctors of the matching individuals within our secure FaceMatch site.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART IN THIS PROJECT?

The main benefit of this project is the potential to help families find a diagnosis.

WHAT WILL BE DONE TO ENSURE THAT INFORMATION GIVEN TO FACEMATCH IS CONFIDENTIAL?

Any information collected for this research project will be treated as confidential. Information and photographs are stored securely away from the publically viewed FaceMatch website. All uploaded photographs and data will be encrypted and stored behind a firewall in a password protected computer at the Hunter Medical Research Institute. We will remove your name and your son/daughter's name and give the information a special code. Only the research team can match the names to their code.

De-identified data generated by the computer vision software from the photograph is used for matching purposes. When a facial match is made, images can only be viewed within the secure FaceMatch site by the FaceMatch team and the nominated doctors of the matching participants.

When we write or talk about the results of this project, information will be provided in such a way that people in your family cannot be identified. Images will not be published without additional consent.

WHAT IF YOU CHANGE YOUR MIND?

Participation in this research project is voluntary. It is your choice to let your son or daughter take part in the project. You do not need to agree to participate if you do not want to. If you give your consent and then change your mind, you can withdraw from the project at any time by emailing our team at info@FaceMatch.org.au. You do not need to tell us the reason why you want to withdraw.

WHAT ARE THE POSSIBLE RISKS OF TAKING PART IN THIS PROJECT (for parents who have a child without a diagnosis)

If your son or daughter has a facial match with another individual within the database, information about this match will be sent to your nominated doctor who will contact you.

It is possible that a facial match may not lead to a diagnosis. This could generate concern or disappointment for you. It is also possible that participation in the project may lead to the diagnosis of an inherited form of intellectual disability. This information may have implications for you, your children or other family members.

Even when parents have been searching for a diagnosis to explain the developmental disability in their child, the actual time of diagnosis can be distressing. Support from your nominated doctor and/or a genetic counsellor will be available.

Thank you for taking the time to read this information statement.

If you would like more information about the project or if you need to speak to a member of the research team please contact the FaceMatch team at info@FaceMatch.org.au

If you have any concerns and/or complaints about the project, the way it is being conducted or your child's rights as a research participant, and would like to speak to someone independent of the project, please contact Nicole Gerrand, Manager, Research Ethics and Governance, Hunter New England Health Research Ethics committee on HNELHD-HREC@hnehealth.nsw.gov.au. Please quote reference number 17/05/17/4.06

If you would like to participate in the FaceMatch project, please complete the consent form below. By signing the consent form, you will be agreeing that you have:

- Read, (or had read to you), this information statement and understand its contents.
- Had an opportunity to ask questions and are satisfied with the answers you received.
- Understand the purpose, extent and possible risks of your child’s involvement in this project.
- Voluntarily give consent for your child to take part in this research project.
- Consented to the doctor below uploading photographs & information as explained.

YOUR SON / DAUGHTER’S DETAILS			
NAME		DATE OF BIRTH	
ADDRESS			
POSTCODE			
PARENT / GUARDIAN DETAILS			
NAME			
ADDRESS			
POSTCODE			
PHONE		MOBILE	
EMAIL			

I CONSENT TO PARTICIPATION IN THE FACEMATCH PROJECT AS DESCRIBED IN THE INFORMATION STATEMENT.

In addition, I give the following consent:

(Please tick the boxes next to the statements you are consenting to).

1. OPTIONAL CONSENT TO BE CONTACTED ABOUT FUTURE RESEARCH PROJECTS.

I consent to the FaceMatch team contacting me and my doctor to discuss possible future participation in future ethically approved projects.

2. OPTIONAL CONSENT FOR DEVELOPMENT OF A SCREENING OR DIAGNOSTIC TOOL.

I give consent for the de-identified image of my son/daughter to be used in the development of a screening or diagnostic tool.

<u>PARENT/GUARDIAN NAME:</u>	<u>SIGNATURE:</u>	<u>DATE:</u>

DECLARATION BY CONSENTING CLINICIAN: I have explained the project to the parent/guardian who has signed above, and believe that they understand the purpose, extent and possible risks of their son/daughter’s involvement in the project.

<u>CLINICIAN NAME:</u>	<u>SIGNATURE:</u>	<u>DATE:</u>