

## 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. <https://facematch.org.au/home>

### WHAT IS THE BACKGROUND TO THE RESEARCH PROJECT?

- Following advanced genetic testing, around 50% of people with likely genetic conditions remain undiagnosed
- People with the same genetic condition can often share similar facial features.
- Matching people with similar facial features can help find a diagnosis and discover new genes.

### WHAT IS THE AIM OF THE FACEMATCH PROJECT?

- FaceMatch aims improve the chance of finding a diagnosis by using advanced computer vision technology to match the faces of people with the same genetic conditions.

### WHO CAN PARTICIPATE IN THE FACEMATCH PROJECT?

#### 1) People with a confirmed diagnosis

- Parents can enrol their children (or adult offspring) with a confirmed diagnosis.
- Adults with a confirmed diagnosis can enrol themselves.

(Contributing faces of people with a diagnosis will improve the FaceMatch image database and help other families still searching for a diagnosis).

#### 2) People without a diagnosis

- Parents of children or adults with a suspected genetic condition who have been reviewed by a medical specialist, but remain without a diagnosis can enrol.

### WHAT DOES PARTICIPATION IN THE FACEMATCH PROJECT INVOLVE?

You will be asked to provide:

- Photographs of your son / daughter (or yourself if you are an adult giving your own consent).
- Relevant medical and genetic information.
- With your written consent, your doctor or genetic counsellor can do this on your behalf.
- Within the secure FaceMatch platform, your doctor or genetic counsellor can share the uploaded information and photographs with doctors and genetic counsellors who are also registered in FaceMatch, and are involved in their / your care.

### WHAT WILL HAPPEN TO THE UPLOADED PHOTOGRAPHS?

- Photographs will be matched against all other photographs in the database.
- Matching photographs will be reviewed by the FaceMatch team within the secure site.
- Photographs can only be seen by the FaceMatch team and your doctor or genetic counsellor.

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

The main benefit of this project is the potential for individuals and families to find a diagnosis.

## **WHAT ARE THE POSSIBLE RISKS OF TAKING PART IN THIS PROJECT?**

**(For parents who have a child without a diagnosis)**

- A facial match may not lead to a diagnosis. This could be disappointing for you.
- The diagnosis of an inherited genetic condition may have implications for you, your children or other family members.
- Finding a diagnosis can be distressing for some people. Support from your nominated doctor and/or a genetic counsellor will be available.

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

- Information collected for this research project will be treated as confidential and stored securely away from the publically viewed FaceMatch website.
- All photographs and data will be encrypted and stored behind a firewall in a password protected computer at the Hunter Medical Research Institute.
- All names will be removed and your information will be given a special code. Only the research team can match the names to their code. De-identified data generated from the photograph (not the actual photograph) is used by the computer program for matching.
- 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.

## **WHAT IF YOU CHANGE YOUR MIND?**

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

## **WILL YOU BE INFORMED OF FACEMATCHING RESULTS?**

If the photographs you upload match another individual, FaceMatch will let your doctor or genetic counsellor know and they will contact you.

## **ETHICS**

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District,

## **COMPLAINTS ABOUT THIS RESEARCH**

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, please contact the HNE Research Office, Hunter New England Local Health District, Level 3, POD, HMRI, Lot 1 Kookaburra Circuit, New Lambton Heights NSW 2305. Telephone: 02 4921 4140. Email: [HNELHD-ResearchOffice@health.nsw.gov.au](mailto:HNELHD-ResearchOffice@health.nsw.gov.au) and quote the reference number: 2019/ETH01073

## FACEMATCH CONSENT

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.
- Consent to your doctor/genetic counsellor uploading photographs & information to FaceMatch.
- Understand that the photographs and information will be stored securely.
- Understand that FaceMatch will contact your doctor or genetic counsellor if a facial match is made.
- Voluntarily give consent to take part in this research project.

YOUR SON / DAUGHTER'S DETAILS			
NAME		DATE OF BIRTH	
ADDRESS			
POSTCODE			
PARENT / GUARDIAN / (OR SELF IF ADULT GIVING OWN CONSENT ) DETAILS			
NAME			
ADDRESS			
POSTCODE			
PHONE		MOBILE	
EMAIL			

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

**I CONSENT TO PARTICIPATION IN THE FACEMATCH PROJECT**

In addition, I give the following consent:

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

I consent to the FaceMatch team contacting me, my doctor or genetic counsellor about ethically approved research projects.

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

I give consent for the de-identified image of my son/daughter or self 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>