



Studying the facial features of children with autism spectrum disorders

We would like to invite your family to take part in a study being conducted by the Autism Research Team at the Telethon Kids Institute. Please read this booklet for more information about this study. If you would like to take part, please contact us using the details at the end of this booklet.

Study Background

Autism Spectrum Disorder (ASD) is a developmental condition characterized by difficulties in social interaction and communication, and a restricted range of activities and interests.

Many developmental disorders are associated with a characteristic face shape. For example, people with Down Syndrome often have a small flat nose, a small mouth, and small ears.

For many years, autism spectrum disorder (ASD) was not thought to be one of these conditions, and certainly at first glance, the vast majority of individuals with ASD do not appear to have a distinctive facial structure. However, several studies that have conducted detailed clinical examinations have indicated that many individuals with autism have small facial anomalies.

On the other hand, members of a family often share similar facial characteristics. This is due to a large proportion of genes shared within a family and genes play a significant role in the development of facial structure.

Face scanning technology, which provides a more fine-grained analysis of a face, may provide even greater insights into the facial features of individuals with autism and their family members.

The current study aims to use the most advanced face scanning technology to scan the faces of children with ASD, as well as their siblings and parents. The study will provide the most detailed and comprehensive investigation of the facial features of a family with a child/children with autism ever conducted.

Aims of this Study

There are three aims of this study:

- 1 To determine whether children with ASD have different facial features to typically developing children.
- 2 To determine whether family members of children with ASD have different facial features to family members of typically developing children.
- 3 To determine whether children with certain behaviours are more likely to have facial anomalies.



Why has my family been chosen?

You and your family have been approached because you have a child who has previously been diagnosed with ASD, aged between 3 and 10 years.

What will this study involve?

Once you have expressed your interest in the study, the Study Coordinator (Anna Hunt) will phone you to arrange the testing session. This study involves one testing session, which will be approximately 30 minutes in length. When you arrive at the Telethon Kids Institute, your family will be greeted and led to one of our testing rooms, which will house the face scanner. The scanner (called a '3dMD scanner') consists of two 'pods' placed on either side of the face. Each pod has two cameras (colour and infra-red) and one projector, which projects a random infra-red pattern on the face. The colour cameras capture facial texture which is mapped on the 3D face model. Scanning is completely painless and has no ill-effects on you nor your child. Scanning time is extremely quick – about two milliseconds.

When your family enters the room, we will ask each of you to sit down on a chair placed in front of the scanner. We will ask you to sit as still as possible while looking directly at the camera. You will then be asked to make a neutral facial expression (verbal instructions: "closed mouth, no smile, no visible teeth and no raised eyebrows). If your child is unable to understand verbal language, we will ask for your assistance with this phase. A 2-dimensional and a 3-dimensional scan will be obtained, which we expect will take approximately 10 seconds. We would be happy to load a copy of the three-dimensional scan onto a CD or USB as a memento. We will ask you to complete some questionnaires about yourself and your child/children, including questions about their social behaviours, communication and overall functioning. These questionnaires should take no longer than 15 minutes to complete.

What are the benefits of participating in this study?

At the conclusion of the session, all children will be asked if they would like a CD or USB with the image of their scanned face. Many children (and caregivers) find this extremely interesting. The results from this study may help reveal more about the causes of ASD. You could be part of a significant scientific advance.

What are the disadvantages of participating in this study?

The scanning machine is not transportable and you will be asked to come to the Telethon Kids Institute for your child's face scanning. The scanning itself is very quick (2 milliseconds), but the whole session will take approximately an hour of your time.

Some people may feel uncomfortable with us storing images of their child's face. Importantly, images will be used for this study only, and will only be seen by members of the research team.

How and where will the information collected be stored?

Any information that we collect from your family will remain private and confidential. We will use the information only for this study.

The information gathered will be de-identified, meaning that we will remove any information with your name on it and give the information a unique code number. Only the research team will be able to match the images to this code number, if it is necessary to do so. For example, if your child has had a clinical assessment with our team (including a videotaped diagnostic assessment), we can use this collected information and link it to your code number for this study. All information collected in this study will be linked to other members of your family who participate. All written information will be stored securely in a locked filing cabinet at the Telethon Kids Institute. Electronic information will be stored on a password-protected computer database at the Telethon Kids Institute (Subiaco) and the University of Western Australia (UWA). We will only disclose information with your permission, except as required by law.

Your family's names, images, and any other identifiable information will not appear on any reports that may arise out of this study, unless you provide consent to do so.

Who is part of the Research team?

The research team is led by Andrew Whitehouse at the Telethon Kids Institute, and the other team members are Anna Hunt (Telethon Kids Institute), Murray Maybery (School of Psychology at UWA) and Ajmal Mian and Syed Zulqarnain Gilani (both from the School of Computer Science and Software Engineering at UWA).

When will my family be informed of the results of from this study?

At the end of each year, we will send you a newsletter that will inform you about the progress of the study, as well as the other research taking place in our group. We are unlikely to be able to inform you of the findings from this research until the conclusion of the study. However, at the end of each year, you will receive a newsletter that will inform you about the progress of this study and our other autism research studies taking place at the Telethon Kids Institute.

Does my family have to participate in this study?

No. Participation in this study is entirely voluntary. You are free to withdraw your consent to participate in this study at any time. Your decision to withdraw consent will not influence your child's further clinical management. All decisions made by your family will be respected by all members of study team.

Who is funding this research?

This research is funded by the Telethon Kids Institute.

Is this study approved?

This study has been approved by the Human Research Ethics Committee of the University of Western Australia. If you have any concerns or complaints regarding this study, you can contact the Human Ethics Office at the University of Western Australia on (08) 6488 3703 or by emailing to humanethics@uwa.edu.au. Your concerns will be drawn to the attention of the Ethics Committee who is monitoring the study.

Who do I contact for more information about this study?

If you would like to discuss anything about this study, or get more information please contact the Study Coordinator, Anna Hunt by phone (08) 9489 7721 or email: Anna.Hunt@telethonkids.org.au

What do I need to do next to participate in this study?

If you are interested to be involved in this study, please complete the Expression of Interest Form (attached) and return in the reply-paid envelope (enclosed) to the Study Coordinator. Or contact Anna Hunt by phone (08) 9489 7721 or email: Anna.Hunt@telethonkids.org.au.

We sincerely thank you for your consideration and look forward to hearing from you soon.