

# Understanding our Research Social Story Children's Version

For NeuroDev South Africa  
By Claire Fourie

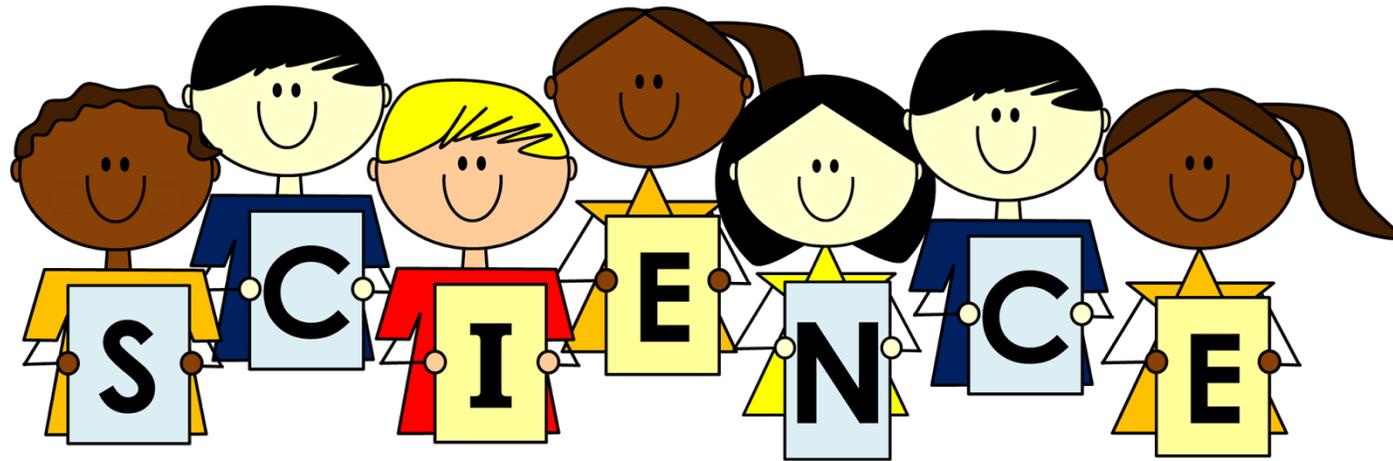
# RESEARCH

Research is an organized way of collecting information to answer hard questions. We are doing research to:  
find out about causes of diseases and to  
help prevent them and treat them.



## WHY?

Our question is why some children have difficulties making relationships and learning new things.



**Before we start the research process, we need to make sure that you understand and agree to take part.**



## WHO?

This study is being carried out by the University of Cape Town and scientists in the United States at Harvard University.



HARVARD  
UNIVERSITY



## WHO?

Some children in our study have difficulties with their thinking and making friends and others do not. We are going to have **thousands** of children from different countries in our research.



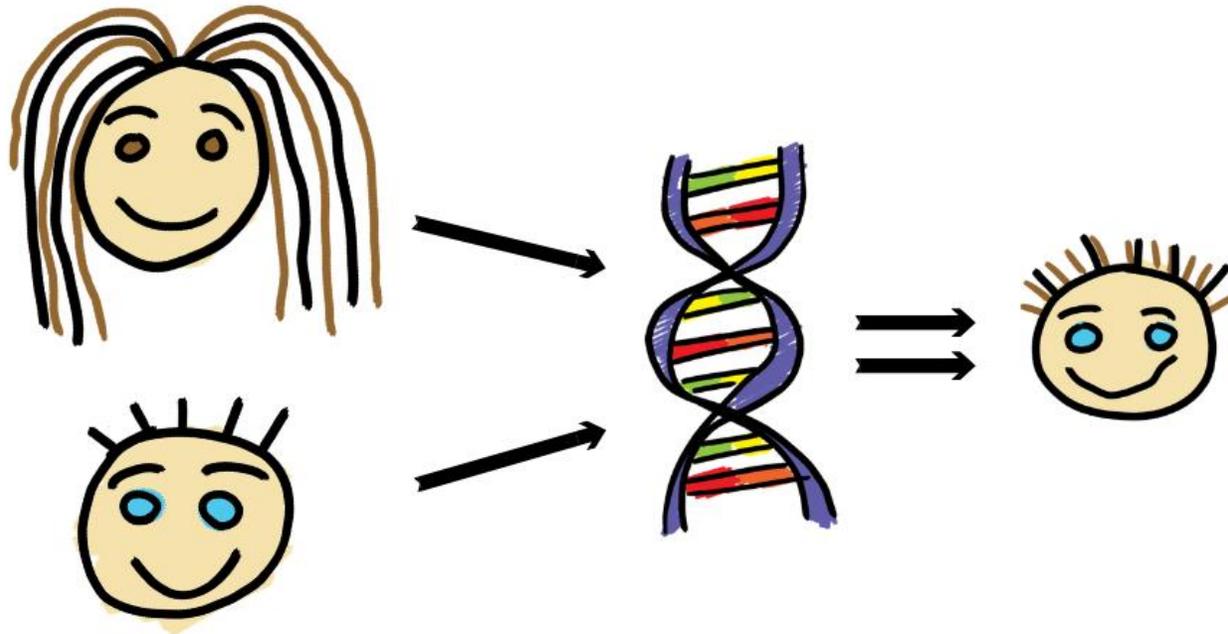
## WHAT?

We want to find out if there is something in our **DNA** that causes these problems.



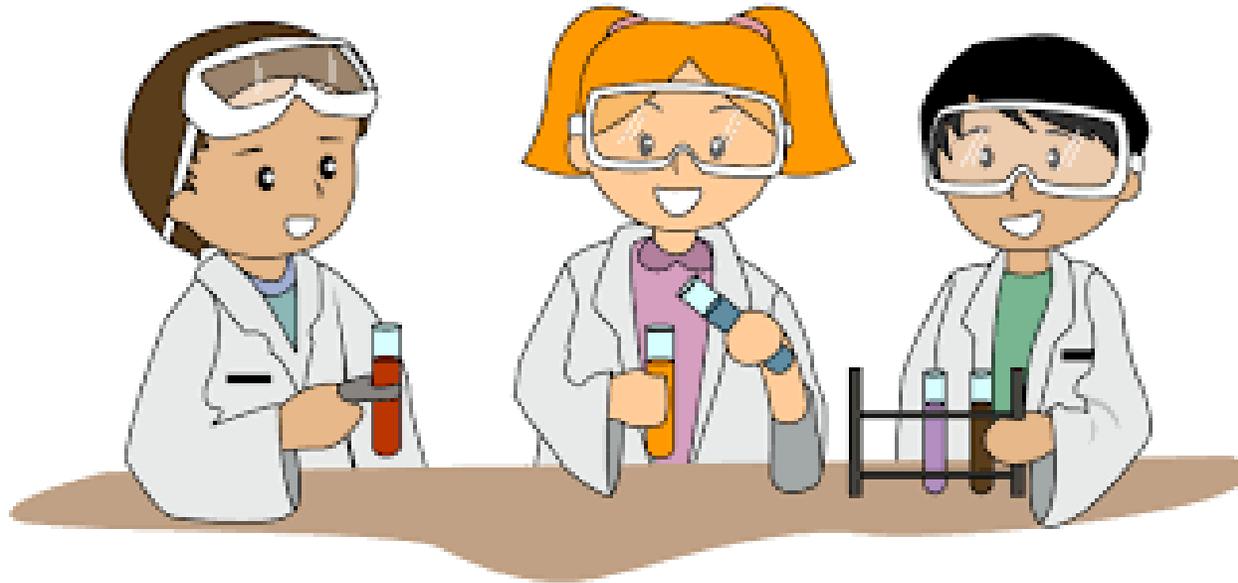
# DNA

DNA are in all the cells that make up our body. We get our DNA from both of our parents. This is why some people might say you look like your mom or like your dad.



# GENETICS

Our DNA are the **instructions** that tell cells to do different things in our body. The science of DNA is called **genetics**.



**We can get DNA from blood and from saliva (another word for spit).**



# PARTICIPATION

For our research we will ask you to:

- Give us some of your blood and maybe some of your saliva
- Ask you and your parents some questions
- Ask you to do some activities, like puzzles and games
- Take your photo

You **do not have to** take part in the study. You can decide if you want to take part or not, this is called **voluntary participation**. You can also decide later that you do not want to be part of the research.

# Voluntary

## **RISKS**

**When we take your blood, it might be a little bit sore for a short time and there might be a little bruise or you might feel a bit dizzy.**



## RISKS

The information we collect about you will be stored in a group of computers called “the Cloud”. People get onto the Cloud by using the internet.



## **PROTECTION**

**Our information is protected with special passwords. The way your information is stored is coded (or changed) by using a barcode so no-one will know that it is you.**

**Your name will also not be stored anywhere.**



## RISKS

It probably won't happen, but there is a small chance that someone can break into the Cloud and look at your information. People might also recognize you from your photo, even though your name will not be on it.



## **BENEFITS**

If you take part in our study you might help other children in the future by helping us learn more.



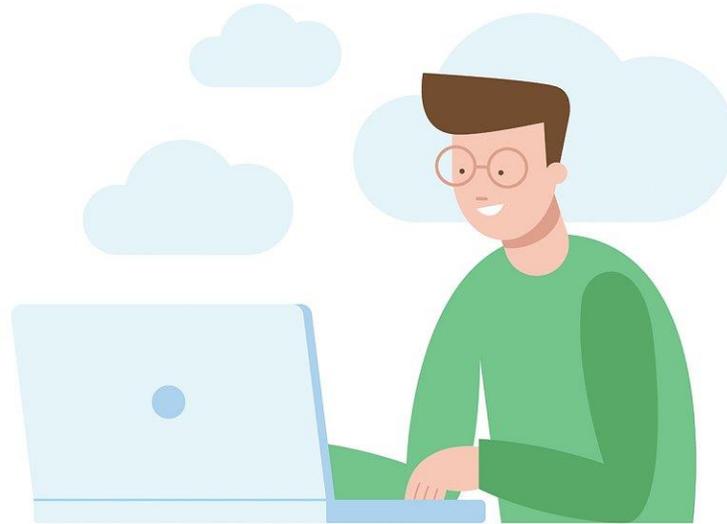
## STORAGE

Your blood and saliva will be sent to our laboratory in the United States and in South Africa where the scientists will have a look at it.



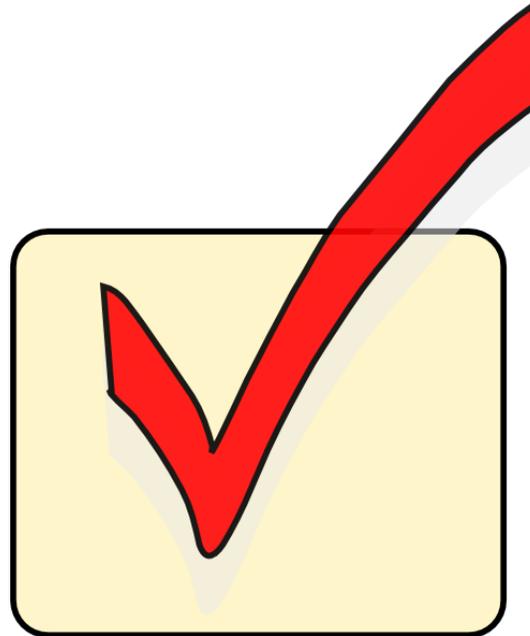
## ACCESS

Some of the results the scientists get will be made available on databases that anyone can access. But, none of the information will have your name on it. It will only say if you are a boy or a girl, where you are from and what ethnic group you belong to.



# CONSENT

If you agree to take part, your parent will fill in and sign a form. This form says that you understand what we have told you and that you agree to take part.



**Any questions?**

