

# The DSD Registry

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## What are DSD?

The way that genital and reproductive organs develop is a complicated process. Sometimes, it does not occur as planned and a child's anatomy does not develop in a typical manner. In other children, there are differences in their hormones or chromosomes. Healthcare workers call the group of medical conditions that affect genital appearance or reproductive function "disorders of sex development" or "DSD." DSD are rare conditions that are present at a child's birth. Sometimes they are noticed close in time to a child's birth. Other times, they go unnoticed for months or years.

## What is a DSD Registry?

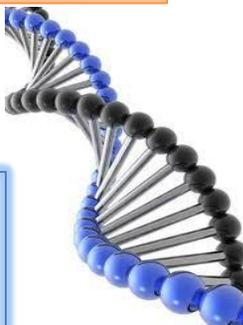
- A registry is a repository of information.
- The purpose of a registry is to collect information from people who share a certain feature.
- In this case, we are collecting information about people who have DSD.
  - DSD are rare conditions, so, without a registry, it could take decades for an individual doctor or researcher to identify enough families and collect the key information needed to answer important questions like, "*what genes are responsible for DSD*" or "*what is the best way to diagnose a DSD*" or "*how do we help parents talk to their children about DSD?*"
- By gathering all of this information into a centralized place, a registry can help speed the pace of research that can tell us more about best practices in health care.

## Are there possible benefits or disadvantages to joining the registry?

- You/your child might not experience direct benefits of participating in the registry.
  - Instead, it is designed to help doctors improve their understanding and care of affected children and adults.
- There are no disadvantages to being included in the registry that we can see.
- We will keep your/your child's information strictly confidential and handle information in the same way that hospitals handle other information about patients.
  - Since the registry will involve collecting information from different hospitals, the system will be password protected and only those directly involved with the registry will have access.

## How do we join?

- Adults will be asked to read over the "Informed Consent" and older children will read over the "Assent" form.
- Please ask us about any questions you have.
- Once you know the full information, then sign and return the documents to us.



## How is this funded?

This project is currently funded by the National Institutes of Health under the project name "Disorders/Differences of Sex Development (DSD): Translational Research Network."