

# INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE)

## Building a Diverse Community for Down Syndrome Research

### Listening Session #1—Families

May 17, 2022

#### Welcome and Overview

*Sujata Bardhan, PhD, Director for INCLUDED Outreach*

Dr. Bardhan welcomed attendees and said that the purpose of the workshop was to continue to build a diverse community for Down syndrome research. Ms. Garcia reviewed the agenda and said that the objectives of the meeting were to provide an overview of the INCLUDE project, encourage inclusion and engagement by listening to community stakeholders, and understand the needs of the community in order to engage them in Down syndrome research that benefits them.

#### Overview of INCLUDE and DS-Connect®: The Down Syndrome Registry

*Dr. Bardhan*

Dr. Bardhan presented slides to provide an overview of the INCLUDE project and NIH efforts to fund and conduct clinical research for all health conditions. Two of the goals of the INCLUDE project are to increase both diversity in Down syndrome research and the number of researchers who are studying Down syndrome. In fiscal year 2021, NIH awarded \$65 million for Down syndrome research through the INCLUDE Project. The DS-Connect® registry is a secure, confidential, online survey tool to collect basic health information about people with Down syndrome. It was launched in 2013 and currently has almost 5,500 registrants, but the participant demographics are not diverse when race/ethnicity, socioeconomic status, and education level are considered. Therefore, NIH seeks to support families to encourage more diverse participation in all types of Down syndrome research (e.g., surveys, DS-Connect®, INCLUDE-funded studies, clinical trials). Engaging with diverse communities to learn about positive experiences and identify barriers and challenges can help increase diversity; that is why the INCLUDE team is conducting this listening session and workshops with families on September 20-21, 2022.

#### Listening Session

An outside moderator presented questions to attendees and allowed for open discussion. The questions and

Have you or your loved one with Down syndrome participated in Down syndrome research?

This question was presented as a live poll. The response was 50% yes and 50% no.

Share any positive experiences you have



## Word cloud: Barriers to participation in Down syndrome research

Attendees inserted words into the Mentimeter website to produce the following word cloud, which graphically describes barriers to participation in Down syndrome research.



## What are the barriers to participation in Down syndrome research?

When asked about barriers to participation in research, families described travel distance and expenses, fears of adverse effects or worsening symptoms, mistrust of the government, exclusion of special populations in studies, generational barriers, and not knowing how the data will be used.

*An advocate shared that although her sister participated in drug trials for dementia, some of the research locations were too far away and some experimental studies created too much fear of adverse effects or worsening symptoms.*

*An advocate said that mistrust in the United States government is a barrier. Additional barriers include not knowing how the research will be used or how it could benefit loved ones.*

*An advocate who was a previous leader in a Down Syndrome organization in Puerto Rico said*

*An advocate agreed and said that a consistent message could be disseminated through those national organizations, as well as the Down Syndrome Diagnosis Network (DSDN). The message should answer the question, “What’s in it for me?”*

*An advocate suggested inviting researchers to events and having families who have participated in research in the past speak about their support for research and their successes with it. She suggested the National Down Syndrome Society (NDSS) as another organization that could be helpful.*

*An advocate suggested listening to what families want and providing education on what research is and is not (e.g., it is not a meme on the Internet). Research comes in many forms, including surveys, quantitative, and qualitative. Following up on the outcomes of research—what was done, how they did it, what they learned or did not learn—is important. Results must be explained in plain language that families can understand.*

## How can NIH support your efforts for outreach and advocacy with diverse participants?

Families said that NIH should conduct relevant research, help

