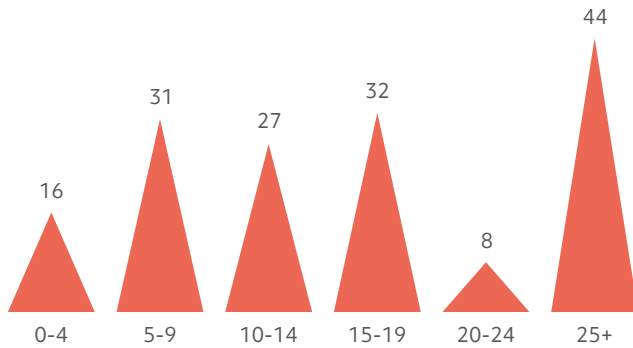


Simons Searchlight Registry Update 16p11.2 duplication

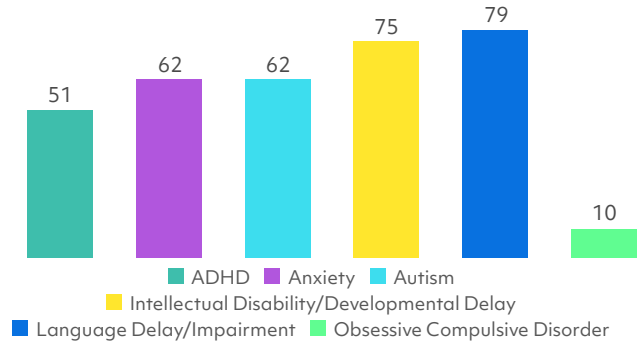
Data in these four graphs are from the medical history information collected in Simons Searchlight from 158 participants with 16p11.2 duplication syndrome.

August 2024

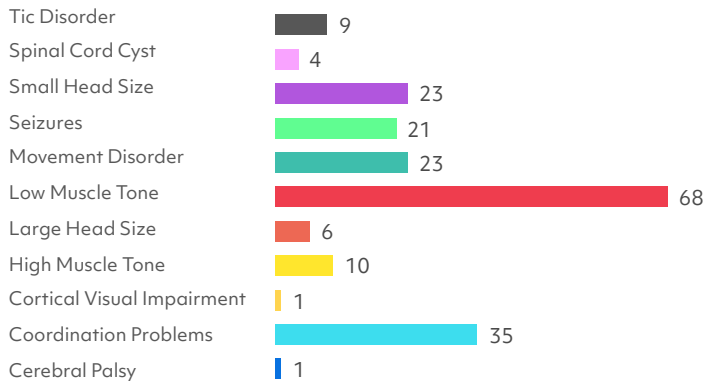
Ages in Years



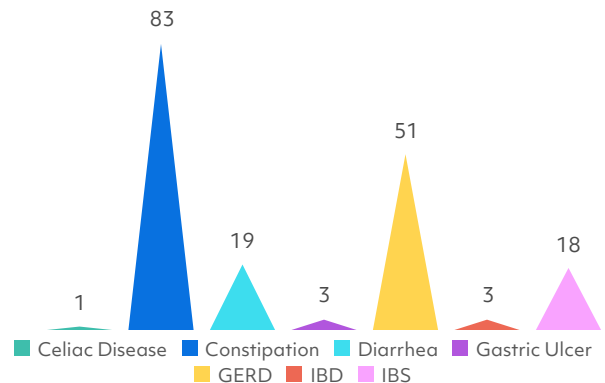
Developmental and Behavioral Conditions



Neurological Conditions



Gastrointestinal Conditions



NOTES: Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.

How to participate?

The information in this report is made possible by the active participation of the 16p11.2 duplication community! Progress for individuals in your community with 16p11.2 duplication is shown below - log in to your simonssearchlight.org dashboard today to check for new surveys and tasks. Your data could hold the clues geneticists need to find answers.



STEP 1

Sign up online

342



STEP 2

Provide your genetic lab report

226



STEP 3

Share your important medical history

165



STEP 4

Fill out surveys

178



STEP 5

Provide a blood sample if you are interested

81



STEP 6

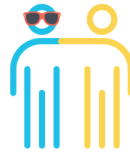
Update us every year

Log in to see next steps

Information Spotlight: Puberty in 16p11.2 duplication

Puberty is a critical time of development and can come with physical and behavioral changes. What does puberty look like in the 16p11.2 duplication syndrome community?

Number of individuals who
started or completed puberty



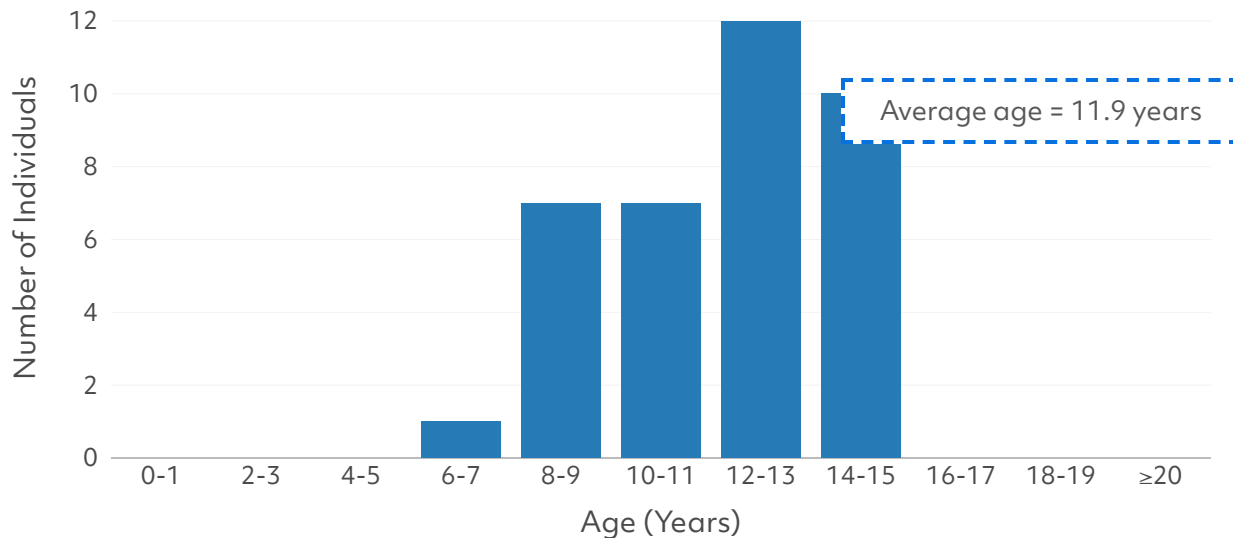
39
Male



72
Total Participants

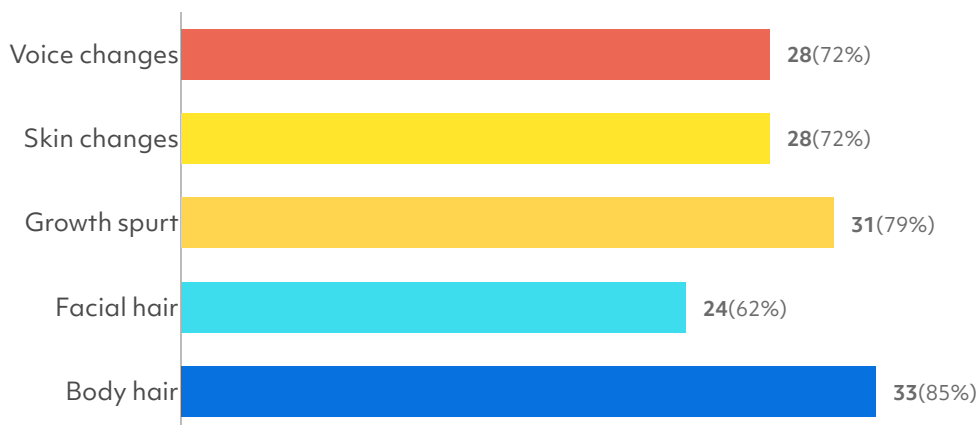
33
Female

Age when **male** individuals **start puberty** (data from 37 individuals)



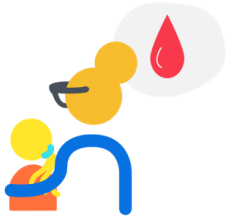
Note: Age data based on reports of when puberty or associated body changes started.

Body changes that **male** individuals experience in puberty (data from 39 individuals; age range shown above)



Some changes happen earlier or later, depending on age and other factors.

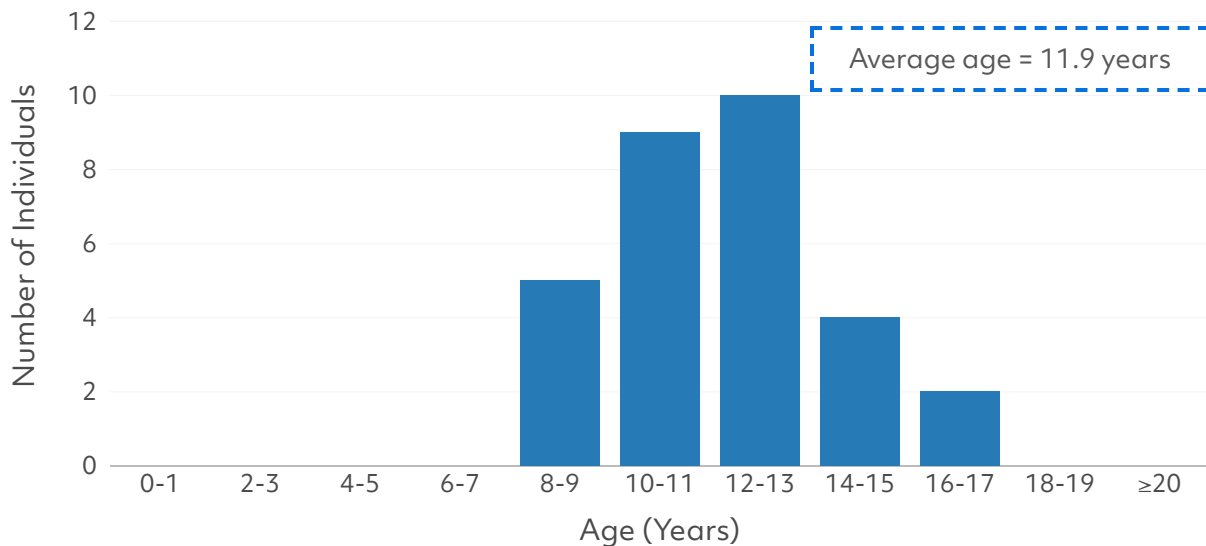
Information Spotlight: Puberty in 16p11.2 duplication



27 (81.8%) **female** individuals report starting menstruation

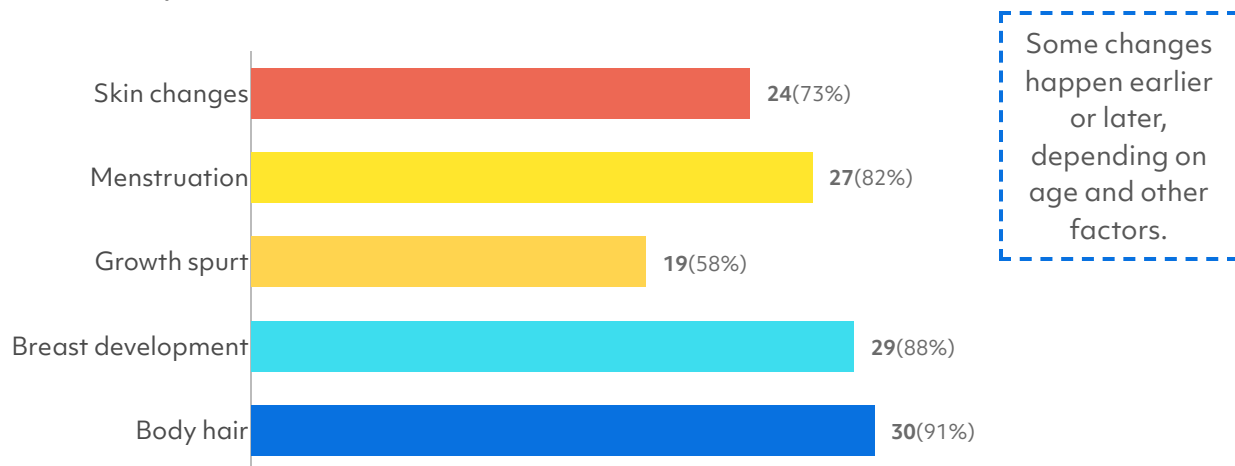
Average age at menstruation: 13.5 years (range: 9-18 years)

Age when **female** individuals **start puberty** (data from 30 individuals)



Note: Age data based on reports of when puberty or associated body changes started.

Body changes that **female** individuals experience in puberty (data from 33 individuals; age range shown above)



Consult a healthcare professional to learn more about managing puberty. Male and female categories based on participants' reported sex at birth. Data are from self-report online research surveys and may contain errors. Questions? Email coordinator@simonssearchlight.org