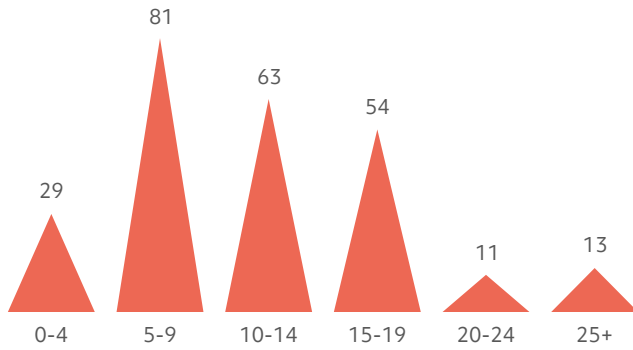


Simons Searchlight Registry Update 16p11.2 deletion

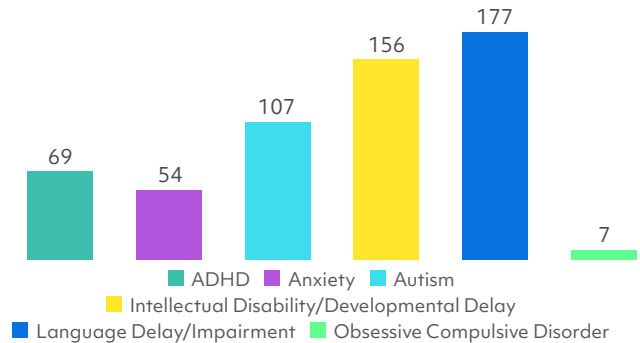
Data in these four graphs are from the medical history information collected in Simons Searchlight from 251 participants with 16p11.2 deletion syndrome.

August 2024

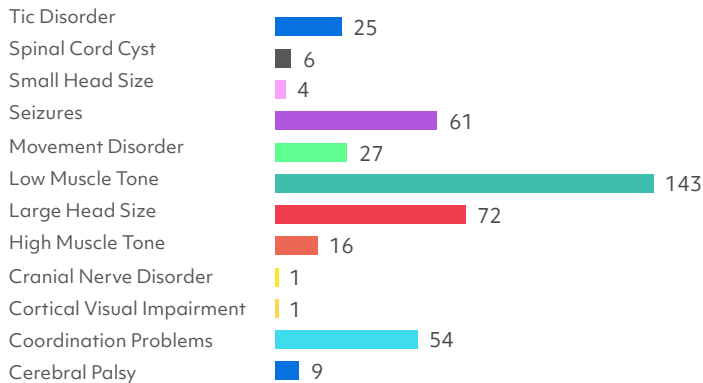
Ages in Years



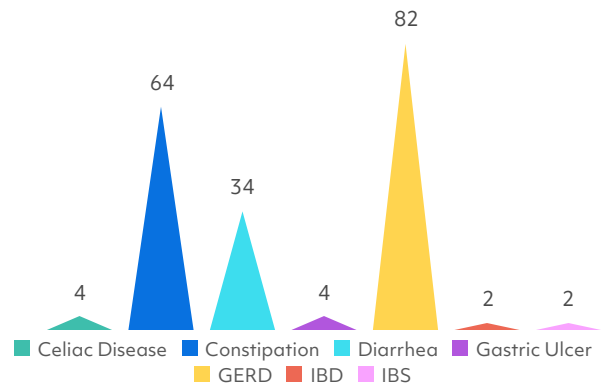
Developmental and Behavioral Conditions



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 deletion community! Progress for individuals in your community with 16p11.2 deletion 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

514



STEP 2

Provide your genetic lab report

328



STEP 3

Share your important medical history

257



STEP 4

Fill out surveys

271



STEP 5

Provide a blood sample if you are interested

112



STEP 6

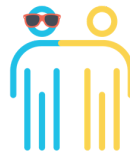
Update us every year

Log in to see next steps

Information Spotlight: Puberty in 16p11.2 deletion

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

Number of individuals who
started or completed puberty



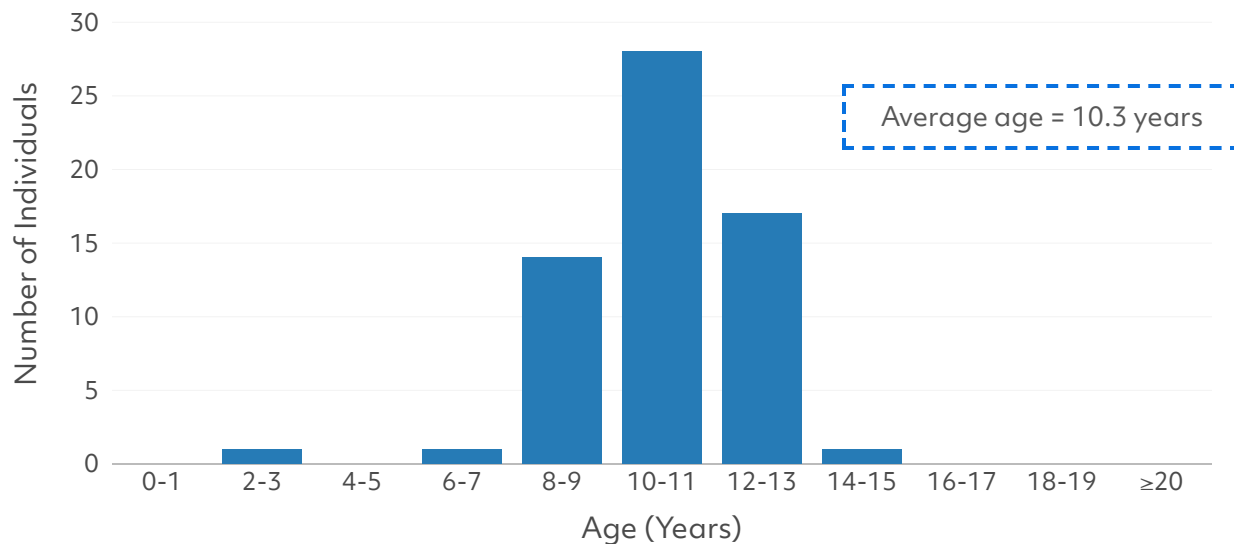
67
Male



60
Female

127
Total Participants

Age when **male** individuals **start puberty** (data from 62 individuals)



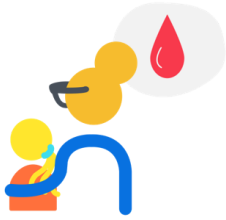
Note: Age data based on reports of when puberty or associated body changes started.

Body changes that **male** individuals experience in puberty (data from 67 individuals; age range shown above)



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

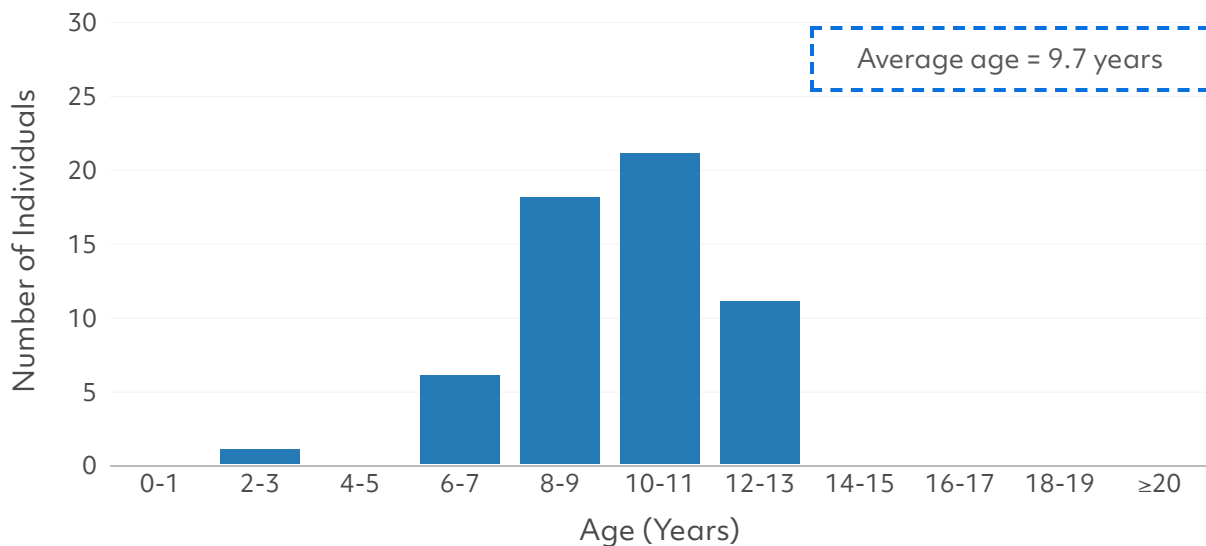
Information Spotlight: Puberty in 16p11.2 deletion



47 (78.3%) **female** individuals report starting menstruation

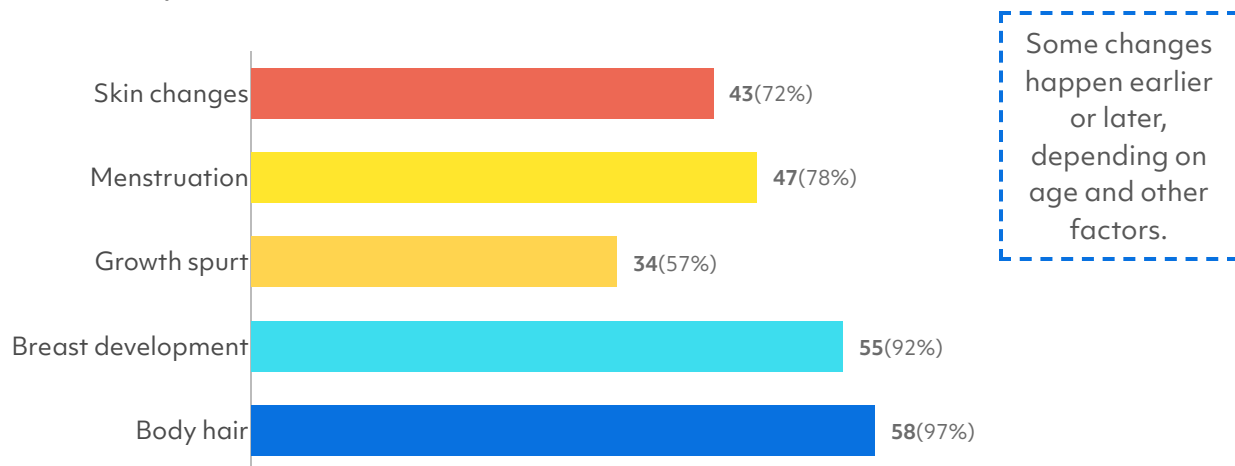
Average age at menstruation: 11.3 years (range: 8-17 years)

Age when **female** individuals **start puberty** (data from 57 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 60 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