

**DNA sequencing data access.** All raw DNA sequencing data for karyotype determination has been deposited in the Project 8p Data Portal (<https://portal.project8p.org/account/signup-researcher>) under project name “Chromosome Engineering for 8p Syndrome”. In order to access the Project 8p Data Portal, all researchers must agree to a legally binding Terms and Conditions document that includes:

- Commitment to non-reidentification of participants.
- Agreement to not redistribute data outside of the approved project team.
- Required acknowledgment and citation of the Onya Portal and Project 8p in resulting publications or presentations.
- Submission of a project update and a brief summary of findings to be shared back with the community.
- Respect for data governance policies developed in partnership with families and advocacy groups.

Access is limited to qualified researchers affiliated with academic, nonprofit, or industry institutions who submit a clear scientific rationale for their intended use of the data. Exclusions may include:

- Requests lacking a defined research question or analytical plan.
- Individuals without institutional affiliation or relevant credentials.
- Requests for commercial use not aligned with the goals of patient benefit or scientific advancement.
- Any requester unwilling to comply with the Portal’s Terms and Conditions.

The Project 8p Data Portal is a strategic initiative of the nonprofit Project 8p Foundation, and data access will be maintained long-term as part of its core scientific and community mission. Sustainability is supported through a combination of philanthropic funding, grant support, and in-kind technical partnerships, including with Amazon Web Services. Should funding conditions change, the data and associated infrastructure will be migrated to a public institutional host or long-term data commons, with mechanisms in place to preserve access and usability for qualified researchers.