



Family Registry Guide

Welcome to the Chromosome 8p Registry! We are so grateful for your participation.

About the Registry

The Chromosome 8p Registry is our secure data collection platform for our Natural History Study. Our Natural History Study collects information directly from 8p Heroes and their families at different ages and life stages to illustrate the full spectrum of 8p rearrangements. Updates shared over time help researchers better understand symptoms, development, changes in needs and help guide future research and care.

About the Biorepository

Our Biorepository collects and processes biological samples, including blood, tissue and cerebral spinal fluid. These samples are donated by 8p Heroes and their families and used by researchers to advance understanding and treatment for 8p.

■ 8P HEROES AND FAMILIES FUEL RESEARCH

Our Partner Researchers like Dr. Matthew Tegtmeier use 8p biospecimens in their research. You can read Dr. Tegtmeier's address to 8p families on the Project 8p website at <https://project8p.org>.

How to Get Started

You can watch the full Registry overview and enrollment process at [Enroll in the Chromosome 8p Registry](#) or follow the steps below!

Step 1 Create Your Account

Go to project8p.org and click "**Enroll My Hero**" at the top right. Then press "**Get Started**" to create a new account.

Already have an account? Click "Login." *Forgot your password?* Use "Forgot Your Password" on the login page. *Not sure if you have an account?* Email engagement@project8p.org.

Step 2 Complete Registration

Fill out the Matrix Registration form. Check your email inbox for a link to set your password and activate your account.

Step 3 Accept Terms & Give Caregiver Consent

Log in, read and accept the **Matrix Terms of Use**. Then complete the **Caregiver Consent form** – this is for *you*. Fill it out with your own information.

Step 4 Enter Your Information

Fill out your **general caregiver information**. You'll then be taken to your caregiver dashboard.

Step 5 Add Your 8p Hero

On your dashboard, click "**Add Participant**" (top left). Fill out the **informed consent** and **general information** for your 8p Hero.

Step 6 Access the Registry

Your Hero will now appear on your dashboard. Click their name to enter the Registry. You'll see surveys ready to complete. *If surveys don't appear right away, log out and log back in*

Step 7 Complete the Surveys

Surveys are in three categories. **Start with the Organ System Involvement Surveys**, then move on to the Core Surveys. You can save your progress and return anytime – surveys do **not** need to be done all at once

Step 8 Upload Your Genetic Report

Upload your genetic report through the registry to unlock your personalized **Patient Passport** (see below).

Step 9 Donate Biospecimens (Optional)

Interested in donating biological samples? Email engagement@project8p.org to schedule a collection.

■ **LIMITED TIME ONLY!** As a thank you to families who complete the full Organ System Involvement Survey Set, Project 8p is randomly giving away **10 FREE registrations** to the **2027 Family and Science Conference**. Finish your surveys to be entered into the drawing!

■ DID YOU KNOW? — The 8p Patient Passport

Project 8p is proud to present our **Patient Passport!** Made uniquely for your 8p Hero, the Passport condenses data collected on 8p Heroes and highlights symptoms and information unique to your hero. This passport can be taken to any medical appointment to help medical professionals better understand your 8p hero.

To get yours, upload your genetic report and complete these surveys:

- Developmental History
- Birth Characteristics
- Medications and Supplements

■ REGISTRY IN ACTION

Thanks to 8p families like you, Project 8p has been able to develop care tools for our community. Using information collected in the Registry, Project 8p has created our **8p Welcome Guide** and **8p Patient Navigators**. Tools made for your hero, from your story — available to use at any time in your 8p Journey.

Why Participate?

Every update you share helps researchers better understand the full spectrum of 8p rearrangements, guiding future research and improving care for the entire 8p community. Your story matters — and it directly shapes tools and resources that families like yours can use every day.

Questions or Need Help?

If you are not sure whether you already have an account, or need any assistance with enrollment, our team is here to help!

Email: engagement@project8p.org

Website: project8p.org