



# Chromosome 8p Registry Checklist

October – December 2026

Your participation is what drives 8p research forward. As we close out 2026, here are our top priorities. Help us finish the year strong by completing what you can before December 31.

## Priority Surveys

Log in to the [Chromosome 8p Registry](#) to complete these surveys:

☐ **Observer Reported Communication Ability (ORCA) (~15 min)**

*Why it matters:* This new survey is collecting baseline communication data from every 8p hero. It's also an endpoint survey for future clinical trials, so making sure it works well for our community now is a first step toward that.

☐ **Changes in Skills & Abilities (~10 min)**

*Why it matters:* Tracks how skills develop and change over time, which is key to understanding how 8p conditions unfold.

## A Bigger Way to Help: Disease Concept Interview

This one is a larger time commitment than the surveys above, so we wanted to call it out on its own rather than bundle it in.

☐ **Join a Disease Concept Model conversation with our Engagement Team (1–2 hours)** — Email [engagement@project8p.org](mailto:engagement@project8p.org) to participate

*Why it matters:* This conversation captures what daily life with 8p is really like, the parts surveys and studies often miss. It directly shapes our research and treatment priorities.

*To schedule, email us with your availability.*

## Optional

☐ **Share a favorite 2026 photo** — Please submit using our [Media Release Form](#)

*Why it matters:* We love celebrating our 8p Heroes! Photos may be featured in our year-end recap and website updates.

**Please complete by December 31, 2026.**

Questions about any of these items? Contact the Patient Engagement Team at [engagement@project8p.org](mailto:engagement@project8p.org). Thank you for helping us finish 2026 strong!

**Together Towards Treatment**