

# Preliminary Results of the RPH Preconception Survey

Through the Reproductive and Perinatal Health (RPH) Initiative, the TSC Alliance seeks to better understand the reproductive needs of the TSC community. To do that, in 2025, we launched a survey regarding pregnancy and/or family planning for individuals with TSC. This was the first in a series of community surveys focused on collecting real-world data with the goal of further supporting individuals and families impacted by TSC.

The RPH Preconception Survey focused on the information provided to individuals prior to pregnancy and specific factors influencing their decision to become pregnant. Criteria for participation in the study included women aged 18–59 years residing in the US or Canada. Seventy-two individuals completed the survey, which included 48 individuals with TSC and 24 caregivers of individuals with TSC. Almost half of the caregivers responding also had TSC themselves.

## Healthcare Providers

- Roughly half of individuals with TSC felt that their obstetrician-gynecologist (OB-GYN) did not have a good understanding of their TSC diagnosis and potential impacts on pregnancy.
- Almost 40% of respondents had shared information about TSC with their OB-GYN providers, most often the contact information of their TSC healthcare provider.
- Surprisingly, 19% of respondents are not currently followed by an OB-GYN.

## Information and Resources

- One third (33%) of respondents had no information about pregnancy planning or reproductive options provided to them.
- When information was given, genetic counselors were the most frequent provider of this information in almost half of respondents. Other common sources were a TSC clinic provider and online searches.
- The TSC community reported that they felt that the following four healthcare providers were most appropriate to provide pregnancy or reproductive options:
  - TSC clinic providers
  - Genetic counselors
  - OB-GYNs
- Maternal fetal medicine specialist (high risk pregnancy doctors)
- One-third of participants received a recommendation or referral to see a prenatal or reproductive genetic counselor.
- Reproductive topics discussed by healthcare providers included the chance to have an affected child, birth control options, concern for pregnancy complications, family planning options (such as adoption, in vitro-fertilization or IVF), and the option of prenatal or preimplantation genetic testing options (testing before implanting an embryo during the IVF process).
- Importantly, 10% of respondents were interested in these reproductive topics, but had not been provided information by their healthcare providers.
- Only 29% of respondents had discussed the avoidance of estrogen-based oral contraceptives with their healthcare provider.

## **Pregnancy Decision-Making Considerations in TSC**

Thirty-eight percent of respondents reported that a healthcare provider told them not to have children due to TSC-related medical problems.

Thirty-eight percent of respondents reported that they, themselves, felt that they should not have biological children because of their TSC-related medical problems with an additional 25% being unsure. The greatest concern regarding pregnancy was having an affected child, followed by the worsening of medical problems and risk for pregnancy complications.

Half of the individuals indicated they were less likely to have a child based on personal experiences of TSC. Conversely, almost one quarter felt that having TSC had not influenced their decision to have or not have children.

Respondents endorsed various challenges and barriers regarding their consideration of pregnancy, some of which may be related to a diagnosis of TSC. These include financial costs of visits/procedures, as well as access to a maternal fetal medicine specialist and specialized medical services/procedures in their state.

### **Next Steps**

The TSC Alliance RPH team plans to address these gaps in care and lack of knowledge or information with future initiatives to improve pregnancy experiences among the TSC community. Further data analysis on the data collected will be performed, and using this information, the team will develop reproductive resources for people interested in this information. These tools will cover a variety of topics including family planning considerations and options, emphasize the importance of routine and specialty healthcare providers, and include the risks of estrogen-based birth control.

Additional efforts through the RPH program are underway to collect relevant data about potential TSC-related risks during pregnancy and develop care recommendations for pregnancy in TSC.

### **The Importance of the Community Voice – We Need You!**

We all benefit from the valuable information collected from the community, and the TSC Alliance will continue to seek community perceptions and experiences through the RPH series of surveys. Stay informed about upcoming surveys through the TSC RPH Initiative webpage and by emailing [RPH@tscalliance.org](mailto:RPH@tscalliance.org) to be added to a communication list.

*The RPH Preconception Survey was developed and summarized by Kate Richardson, MS, CGC, Elizabeth Cassidy, MPH, and Heather Radtke, MS, CGC in conjunction with the RPH Reproductive Task Force.*