

Rett Syndrome Family Survey

Principal Investigator: Drs. Anita Datta

**Co-Investigators: Drs. Gabriella Horvath
and Zeinab Gholibeigian**

Caregivers of patients with Rett Syndrome (RTT) are invited to participate in an anonymous virtual survey to help us learn about caregiver perspectives on priorities for care.

Goal: To identify areas where RTT caregivers and clinicians agree and disagree in care priorities in order to make care better for families.

Who can participate?

- Caregivers of RTT patients in Canada
- Age 19 or older
- Able to complete survey in English

What does the study involve?

Study participation involves completing one **10-15 min** survey.

How do I participate?

Scan the QR code below to learn more about the study!

Survey link:

<https://rc.bcchr.ca/redcap/surveys/?s=9MJLYE8KWDCPCMRN>



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Study Dates: Sep 2025 - Sep 2026

Study Contact: leo.yang@cw.bc.ca