

Connor's Clinical Trial Experience: A Case Study (2023)

Disclaimer: PCNA shares personal experiences to help illustrate real-world considerations. Individual situations vary, and stories like the one below are intended for educational purposes only. Every clinical trial is different. Costs, eligibility criteria, locations, and available financial supports vary from study to study and over time. The experience shared below reflects one individual's situation in 2021 and involved travel from Canada to participate in a U.S.-based clinical trial. Current processes, requirements, and costs may differ today.

In 2023, Connor participated in a clinical trial studying RMC-6236 (Daraxonrasib), a novel investigational therapy targeting KRAS mutations. At that time, the trial was offered at ten sites across the United States, with no participating sites in Canada. There were significant waitlists at many of the institutions.

Connor's family contacted each of the ten trial sites to understand their process for joining a waitlist. This included confirming whether an initial consultation was required and what the associated costs would be. In some cases, an upfront consultation fee of approximately \$14,000 USD was required in order to be added to the waitlist, with no guarantee of a trial spot becoming available. For one trial they pursued, these costs covered the duration of the trial, approximately seven months, and included appointments, accommodations, and related trial participation expenses. Based on cost and feasibility, they made decisions about which sites to pursue.

Connor was ultimately accepted into the trial at The Christ Hospital in Cincinnati. After accessing financial assistance offered through the institution to help offset travel, meals, and accommodation costs up to a specified limit, the family's out-of-pocket cost for participation in the U.S.-based trial was approximately \$14,000 CAD. A portion of these expenses was later claimed as medical expenses for tax purposes, following consultation with a tax advisor.

Several factors helped make participation more manageable:

- The initial consultation and required appointments at the chosen institution were comparatively affordable.
- The trial oncologist coordinated closely with Connor's Toronto-based oncologist, allowing supportive care medications to be prescribed and managed in Canada. Palliative care also remained in Canada.
- The U.S. hospital connected the family with its financial support department, and grant funding was available to offset certain travel-related expenses.
- Some staging scans, bloodwork, and procedures that were not required to be completed on site were arranged in Canada.

Participating in a clinical trial outside of Canada required research, coordination, and planning. While every situation is unique, this experience highlights the importance of asking detailed questions about costs, financial supports, care coordination, and what can be managed locally. If you are considering participation in a clinical trial, particularly one outside your home province or country, speaking with both the trial site and your local oncology team can help clarify what to expect and what supports may be available.



Jen, Connor and their two boys in 2023