

New Patient-Partnered Research Project for Translocation Renal Cell Carcinoma Launches

Led by the research initiative Count Me In, the project empowers patients with this rare kidney cancer to share their unique health data.

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Count Me In, a patient-partnered research initiative led by Dana-Farber Cancer Institute and the Broad Institute of MIT and Harvard, is launching a new project focused on translocation renal cell carcinoma (tRCC), a rare and aggressive form of kidney cancer. The effort will engage with tRCC patients, empowering them to share their unique health data with scientists to accelerate research on tRCC.

tRCC is a unique type of kidney cancer caused by specific genetic changes called translocations, where parts of chromosomes swap places or rearrange. While tRCC affects individuals across all age groups, it is most commonly diagnosed in children and young adults. Due to its rarity, research on tRCC has historically been limited, leaving patients and families with few therapeutic options and many unanswered questions.

The tRCC Project aims to address these challenges, by partnering directly with patients, caregivers, and advocates to deepen understanding of this rare disease and generate new insights that could lead to new treatments.

Participants can share their medical history, personal experiences, and biological samples through Count Me In's secure online platform. To ensure participant privacy and security, all data will be de-identified before being shared with researchers. Leveraging its connection to the Broad Institute, the study team will utilize cutting-edge genomic sequencing and advanced tools at the Broad Clinical Labs to explore tRCC at a molecular level and drive meaningful discoveries.

"Our mission is to redefine how rare cancers like tRCC are studied by offering all patients an opportunity to share their voice in the research process," said Diane Diehl, director of scientific operations for Count Me In. "By collaborating directly with the tRCC community, physicians and others in the scientific community, and applying Count Me In's unique patient-partnered approach, we hope to uncover critical insights that pave the way for better treatments and improved care for those impacted by this difficult disease."

“Translocation renal cell carcinoma (tRCC) is a rare and aggressive form of kidney cancer that poses significant treatment challenges,” said [Srinivas Viswanathan](#), a physician at Dana-Farber Cancer Institute and an assistant professor of medicine at Harvard Medical School. “By partnering with Count Me In, we have a unique opportunity to engage directly with patients and families impacted by this under-researched cancer. This collaboration will deepen our understanding of the disease and help pave the way for new, more effective treatment options that could improve outcomes for those affected.”

“Count Me In’s patient-driven research model allows us to transform how we approach rare cancers like tRCC,” said [Elizabeth Mullen](#), institute physician and program leader (renal) at Dana-Farber/Boston Children’s Blood Disorders and Cancer Center, and an assistant professor of pediatrics at Harvard Medical School. “Increased access to diverse patient data, including genetic and clinical insights, is invaluable for the research community aiming to better understand this rare disease. Patient data helps us better understand tRCC biology, tailor treatments, and explore new therapies, bringing both scientific progress and renewed hope to those affected by this challenging cancer.”

The tRCC Project is open to anyone in the United States and Canada who has been diagnosed with tRCC. Patients or their caregivers can join the effort to advance research by visiting tRCCProject.org to learn more and enroll.

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