Thank you for your interest in the CCDI Pediatric, Adolescent, and Young Adult (AYA) Rare Cancer study.

This study aims to help researchers learn more about how very rare childhood cancers behave over time. By joining, you could support this effort while also learning more about your own health—with no extra treatments or medication required.

WHO CAN PARTICIPATE?

Kids, teens, and young adults can participate if they:

- **ARE 39 YEARS OLD OR YOUNGER**
- **WERE DIAGNOSED WITH A RARE SOLID TUMOR LESS THAN A YEAR AGO**
- **ARE WILLING TO PROVIDE TUMOR AND SALIVA OR CHEEK SWAB SAMPLES FOR TESTING**

If you are interested in taking part in the CCDI Pediatric and AYA Rare Cancer Study, talk with your doctor or contact the study team to determine if participating is right for you.

If you are under the age of 18, talk with your parent or caregiver about speaking with the study team.

LEARN MORE

cancer.gov/ccdi-rare-cancer

QUESTIONS?

Email NCICCDIRCI@mail.nih.gov

Principal Investigator:
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CHILDHOOD CANCER DATA INITIATIVE

PEDIATRIC, ADOLESCENT, & YOUNG ADULT
RARE CANCER STUDY

JOIN A RESEARCH STUDY

COLLECTING DATA ON RARE CHILDHOOD CANCERS

WHAT HAPPENS DURING THE STUDY?

Screening:

We'll review your medical history and ask questions to make sure that this study is right for you.

Consent:

We'll go over the study and what participation involves in more detail. If you are eligible to participate, we'll obtain consent and any other information or samples needed.

Follow-Up:

During this time, we'll collect information about your health. Depending on whether you are receiving treatment, we will check in approximately every 3–6 months. Total study participation is 5 years.

REMINDERS!

Participating is a choice.
You can ask questions, take breaks, or leave the study at any time.

There will be no experimental treatments or in-person appointments—just surveys, and data and sample collection. Compensation for participating will be provided.

Your treatment will continue at your home hospital and your usual health care will not be affected by participation in this study.

MORE FAQs:

What is the CCDI Pediatric and AYA Rare Cancer Study?

It is a longitudinal, observational study focused on collecting different types of health and genomic data from people with very rare childhood cancers.

The information collected during the study will go into a database that researchers can use to better understand how or why these cancers develop and how they behave over time, so that they can find effective ways to treat people with very rare childhood cancers.

What is a longitudinal, observational study?

It's a type of study that tracks how a disease progresses over time. It helps researchers learn more about a disease and how to best treat it.

What is the Childhood Cancer Data Initiative?

The Childhood Cancer Data Initiative (CCDI) is a National Cancer Institute program working to make it easier to find and share deidentified childhood cancer data, so that researchers have the information they need to make more and better treatments. Through projects like the Pediatric and AYA Rare Cancer Study, CCDI aims to help make faster progress in childhood cancer research.