

Consent and Release Form

Background:

The Maternal Infant Child and Youth Research Network is a not-for-profit academic research organization dedicated to advancing knowledge and improving outcomes in maternal, child, and youth health.

RareKids-CAN: Pediatric Rare Disease Clinical Trials and Treatment Network (“RareKids-CAN”) is a Canadian Institutes of Health Research (CIHR)–funded national initiative that brings together a diverse coalition of partners with a shared goal of simplifying and streamlining pediatric rare disease clinical trials and improving access to innovative treatments for children, adolescents, and young adults across Canada. RareKids-CAN is housed within and administered by MICYRN, which serves as the legal entity responsible for its operations and activities.

This Consent and Release Form includes important information about MICYRN/RRSEM (“MICYRN”) making and use of photographs, audio/visual videos, or other reproductions of you (“Recordings”) for RareKids-CAN initiatives, events, communications, and knowledge mobilization activities. While these Recordings are being collected and used for RareKids-CAN purposes, the consent is being obtained by MICYRN, in its role as the legal entity responsible for RareKids-CAN.

Please read this Consent Form carefully and feel free to ask questions.

1. I give MICYRN permission to make Recordings of me.
2. I give MICYRN permission to publish, distribute, and/or broadcast the Recordings or any parts of them in any media worldwide for MICYRN’s publications that are aimed at the purpose of promoting MICYRN’s goals (“**Purposes**”), which include:
 - a. advancing the knowledge and study of child and maternal health, and
 - b. promoting child and maternal health by developing best practices and national standards for research, coordinating research projects, and distributing research results.
3. When MICYRN uses the Recordings for its Purposes, I agree that the Recordings are the property of MICYRN for those Purposes.
4. I understand that MICYRN may choose not to use the Recordings.
5. I understand that I will not be paid for the making or use of the Recordings.
6. I understand that I can revoke this permission at any time and for any reason by contacting rarekidscan@micyrn.ca. I understand that if I do so:
 - a. MICYRN will remove any postings of me that it can and will not make any further use of the Recordings, and
 - b. MICYRN will not be able to retrieve any Recordings that were previously published, distributed, or broadcast.
7. I will not take any action against MICYRN for its making, publishing, distributing, and/or broadcasting of the Recordings in accordance with the scope of my permission