Canadian Retinoblastoma Research Registry
Data Access Request Form

As a part of the Canadian Retinoblastoma Research Registry (CRRR), registrants can choose to be contacted by the research team and/or external researchers regarding research opportunities (to participate in a research study and/or if there is a position available on the research study team). Please complete the Data Access Request form and email the signed PDF to retinoblastoma.research@sickkids.ca.

Section 1: Applicant Information

PRINCIPAL INVESTIGATOR INFORMATION:

Principal Investigator Last Name: _____
Principal Investigator First Name: _____
Title: _____
Email: _____
Position: _____
Institution Name and Address: _____

PRIMARY CONTACT PERSON FOR CORRESPONDENCE:

Last Name: _____
First Name: _____
Title: _____
Email: _____
Position: _____
Institution Name and Address: _____

PERSONS WHO WILL HAVE ACCESS TO THE DATA:

Last Name: _____
First Name: _____
Institution: _____

Section 2. Ethics Board Approval

Please attach a copy of REB certificate or equivalent.

Organization: _____
Certificate Number: _____
Expiry Date: _____

Section 3. Research Project Description

Project Description	

Project Contact Information

Please share the project description and contact information on RB Canada Research:

- ☐ Yes
- ☐ No

Project Objectives

Requested Data Justification

Section 4. Defining Registrant Data

I am requesting the following:

- ☐ For the CRRR study team to share research study with applicable registrants.
- ☐ To receive applicable registrants' contact and personal information for research study.

Description of Study Population

Description of Study Team Member

DEMOGRAPHIC INFORMATION OF REQUESTED REGISTRANTS:

1. Age

- ☐ 10 – 14 years
- ☐ 15 – 19 years
- ☐ 20 – 24 years
- ☐ 25 – 29 years
- ☐ 30 – 34 years
- ☐ 35 – 39 years
- ☐ 40 – 44 years
- ☐ 45 – 49 years
- ☐ 50 – 54 years
- ☐ 55 – 59 years
- ☐ 60 – 64 years
- ☐ 65 – 69 years
- ☐ 70 – 74 years
- ☐ 75 – 79 years
- ☐ 80 – 84 years
- ☐ 85 – 89 years
- ☐ 90 – 94 years
- ☐ 95 – 99 years

2. Sex

- ☐ Female
- ☐ Male

3. What language spoken most often at home

- ☐ English
- ☐ French
- ☐ Other:_____

7. Population group(s):

- ☐ White
- ☐ Chinese
- ☐ South Asian
- ☐ Black
- ☐ Filipino
- ☐ Latin American

- ☐ Southeast Asian
- ☐ Arab
- ☐ West Asian
- ☐ Korean
- ☐ Japanese
- ☐ First Nations or Aboriginal (including Métis and Inuit)
- ☐ Other: _____

8. Religion
   - ☐ Buddhist
   - ☐ Christian
   - ☐ Hindu
   - ☐ Jewish
   - ☐ Muslim
   - ☐ Sikh
   - ☐ Traditional (Aboriginal) Spirituality
   - ☐ No religious affiliation
   - ☐ Other: _____

9. Place of residence
   - ☐ Rural area (less than 1,000)
   - ☐ Small population center (1,000 to 29,000)
   - ☐ Medium population center (30,000 to 99,000)
   - ☐ Large urban population center (100,000 or greater)

10. Address Information:

City: _____

Province: _____

RETINOBLASTOMA INFORMATION OF REQUESTED REGISTRANTS:

Relationship with retinoblastoma
- ☐ Survivor
  - Diagnosed:
    - ☐ 10 – 19 years ago
    - ☐ 20 – 29 years ago
    - ☐ 30 – 39 years ago
    - ☐ 40 – 49 years ago
    - ☐ 50 – 59 years ago
    - ☐ 60 – 69 years ago
    - ☐ 70 – 79 years ago
    - ☐ 80 – 89 years ago
    - ☐ 90 – 99 years ago
- ☐ Mother or father of (a) child(ren) with retinoblastoma
  - Number of children diagnosed with retinoblastoma?
    - ☐ 1
    - ☐ 2
    - ☐ 3+
  - Child(ren) diagnosed
    - ☐ Less than 1 year ago
    - ☐ 1 – 5 years ago
    - ☐ 6 – 10 years ago
    - ☐ 10+ years ago

☐ I do not have a child affected by retinoblastoma

☐ Other: _____

Section 5. Terms of Use: Data Security and Access

DATA ACCESS PROCESS

The Canadian Retinoblastoma Research Advisory Board's (CRRAB) Research Advisory Working Group will review all data access approximately every 6 weeks. The working group will ensure all components of the form are valid in order to approve or reject requests or ask for additional information.

If approved, the Research Advisory Working Group will submit an amendment to REB, including the application of the SickKids scientist named as Co-Investigator and legal. All suitable registrants, using the lease amount of information necessary for the research project, will be extracted from the registry and sent to the study's PI, using OneMail or Secure File Transfer. Data shared with external researchers will be governed by the confidentiality practices at their institutions. Altogether, data access requests have a two- to three-month turnaround period.

DISCLAIMER

The following disclaimer must be used when disseminating or publishing any output that references data received from the CRRR:

"All inferences, opinions, and conclusions drawn in this publication are those of the authors, and do not reflect the opinions or policies of the Canadian Retinoblastoma Research Advisory Board."

PATIENT CONTACT

Patients can only be contacted (1) regarding the approved project, (2) by the study team or external study team members listed in the Data Access Request Form, and (3) once the request has been approved by CRRAB's Research Advisory Working Group and REB. The PI is responsible for contacting applicable registrants that have given permission to be contacted by both the study team and external researchers. Contact must be made through the patient's preferred form of contact (email or phone) or at the PI's preference if patient has selected both options.

Section 6. Signatures and Declarations

If data request is approved, the study team, including members stated above, will only contact applicable registrant regarding _____ (*study name*) with REB approval # _____.

I have read, understand and agree to the above conditions.

Principal Investigator Name: _____

Principal Investigator Signature: _____

Date: _____