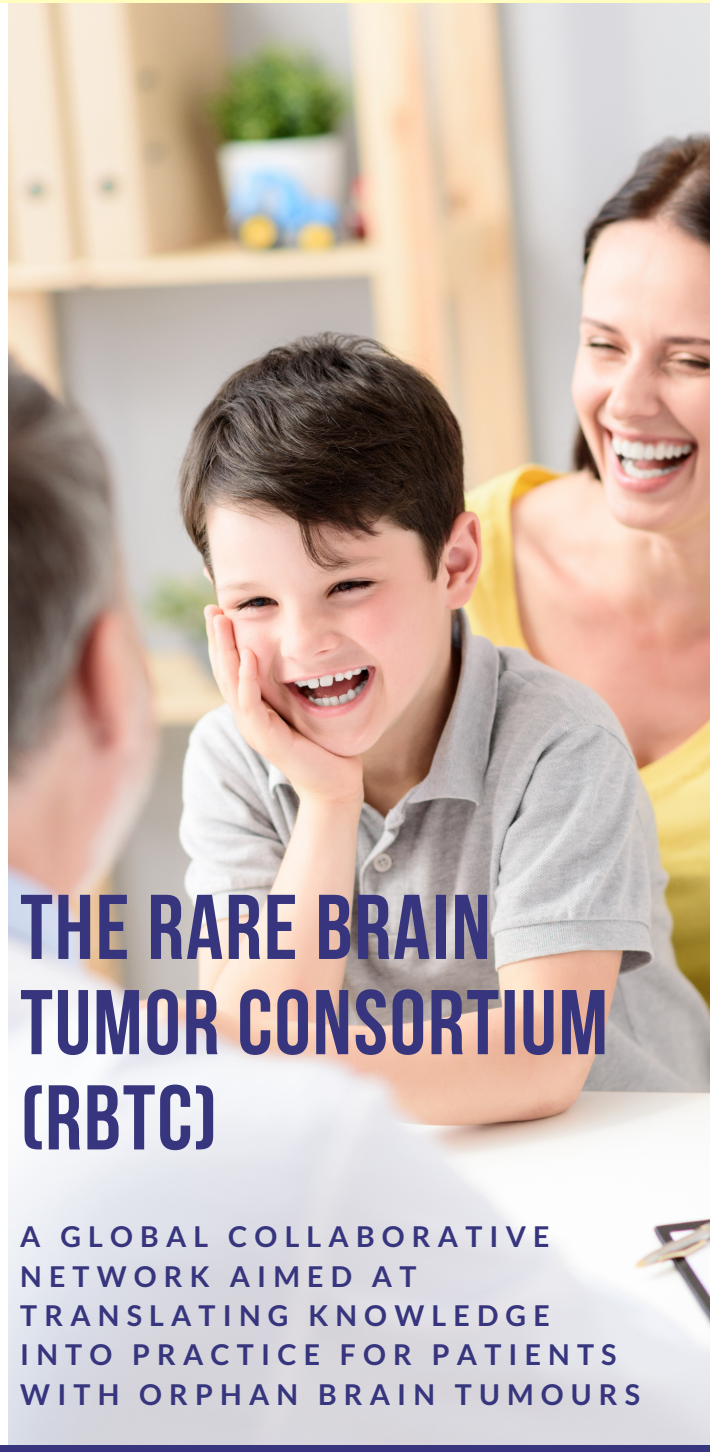
RBTC ACCOMPLISHMENTS

- **Discovery of epigenetic subgroups with variable therapeutic sensitivities in atypical teratoid rhabdoid tumors (ATRT)**
  (Torchia et al. Lancet Oncology 2015, Torchia et al. Cancer Cell 2016).
- **Discovery of C19MC as a novel biomarker in an aggressive subgroup of CNS-PNET**
  (Li et al. CancerCell 2009).
- **Discovery that ETMRs comprise a spectrum of historical histologic diagnoses**
  (Spence et al. Acta Neuropath. 2014, Spence et al. Neuro-Oncology 2014; Picard et al. Lancet Oncology 2012, Korshunov et al., Acta Neuropath. 2012).
- **Identification of therapeutic vulnerabilities in ETMRs and ATRT**
  (Sin-Chan et al.Cancer Cell 2019, Torchia et al. Cancer Cell. 2016)
- **Development of radiation sparing protocol for children with ATRTs**
- **Discovery of molecular subgroups of pineoblastoma**
  (Li et al. Acta Neuropath. 2019)

WHY JOIN THE REGISTRY

1. **Molecular profiling**: find out more about your patients
2. **Identify** beneficial treatments for a subgroup of patients
3. **Generate insights** into risk factors for these diseases
4. **Consultations:** discuss therapeutic options and clinical findings with our experts.
5. **Clinical trials:** assist in prospective and retrospective research that can contribute to future trials
6. **Participate** in international collaborations with other scientific groups/committees
7. I**mplement and discover** novel clinically relevant diagnostics for current and future patients
8. **Authorship**: contribute to the scientific community
9. Be a **leader** in developing a **perpetual international registry** for rare brain tumors (akin to the international neruroblastoma registry)
10. **Work together** to change the paradigm of care and outcome for **all** patients with rare pediatric brain tumors

Rare Brain Tumor consortium
Translating knowledge to cures for orphan tumors



THE RARE BRAIN TUMOR CONSORTIUM (RBTC)

A GLOBAL COLLABORATIVE NETWORK AIMED AT TRANSLATING KNOWLEDGE INTO PRACTICE FOR PATIENTS WITH ORPHAN BRAIN TUMOURS

ABOUT US

Rare childhood brain tumors are highly neglected and understudied diseases for which biological and clinical understanding is only beginning to emerge for some but not all tumor entities. The Rare Brain Tumor Consortium (RBTC) was formed in 2003 to bring together clinicians, researchers and patient advocates around the world with an interest in advancing the science and clinical care of patients with rare pediatric rare brain tumors. The goal of the RBTC was to create a comprehensive clinical and molecular data base of various rare brain tumors to not only inform new biological understanding and therapeutic mechanisms but also construction of clinical trials as well as current practical management for these uncommon diseases.

Initially, supported by seed funds from families affected by ATRT and ETMR, the RBTC has generated a worldwide clinical registryand biorepository that is now one of the largest of its kind with over 140 international sites in 60 countries and approximately 3000 tumor samples with well annotated patient clinical data. Materials and clinical data collected through the RBTC has been applied towards discovery and translational studies using multi-omics and more focused methods and clinico-pathologic analyses. These efforts have contributed significantly to development of diagnostic assays as well as tumor sub-typing tools that is now applied in clinical diagnostic labs.

The RBTC has become an internationally recognized network and resource. Collectively RBTC members has contributed significantly to the revised WHO classification of CNS tumors as well as design of clinical trials in consortia like COG, PNOC and CONNECT.

AREAS OF INTEREST

- Embryonal tumor with multiple rosettes (ETMR) which include:
    1. Embryonal tumor with abundant neuropil and true rosettes (ETANTR)
    2. Medulloepithelioma
    3. Ependymoblastoma
- Atypical teratoid rhabdoid tumor (ATRT)
- Pineoblastoma
- Other embryonal brain tumors formerly known as primitive neuroectodermal tumors (PNET or CNS-PNET)
- Embryonal tumor NOS including those reported with FOXR2, BCOR alterations

THE PROCESS

- MTAs, REB are provided for your institutional boards/legal dept approval
- Cost of shipping is borne by the RBTC.
- RBTC Registry and bio-repository managers will provide all necessary information regarding tissue and data collection

WHAT WE COLLECT

- Primary and/or recurrent tumor and/or metastatic tumor
    1. FFPE slides
    2. FFPE curls
    3. Snap frozen tissue (preferred as gives cleanest results with NGS tools)
- Matched blood
- CSF where available
- Clinical data including demographics, disease features, treatment details and outcome).

JOINING THE RBTC

For inquiries please contact:

- Dr. Salma Al-Karmi (Registry Manager) at salma.al-karmi@sickkids.ca
- Dr. Mei Lu (RBTC Bio-repository Manager): meilu@sickkids.ca