

# Clinicians studying rare brain tumours around the world connect through new SickKids registry

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## Summary:

With the goal of accelerating and improving diagnosis and treatment strategies for children affected by these rare and often fatal tumours, a new online registry for rare paediatric brain tumours was launched. The project, known as the Rare Brain Tumour Consortium (RBTC), is led by SickKids.

## By Emily de Medeiros

With the goal of accelerating and improving diagnosis and treatment strategies for children affected by these rare and often fatal tumours, a new online registry for rare paediatric brain tumours was launched. Led by The Hospital for Sick Children (SickKids), this global network known as the Rare Brain Tumor Consortium (RBTC) has collected medical and biological information from nearly 1,000 unique brain tumours to date.

These rare brain tumours in children are also collectively known as embryonal tumours that include primitive neuroectodermal tumours (PNETs) and atypical teratoid rhabdoid tumours (ATRTs). They are estimated to make up five to 10 per cent of malignant brain tumours in children.

“Finding effective treatment options for these rare brain tumours can be challenging because they can often be mistaken for other more common tumours such as medulloblastoma, but these tumours behave differently,” explains [Dr. Annie Huang](#), lead of the RBTC, Staff Oncologist in the Paediatric Brain Tumour Program in the Division of Oncology/Haematology and Senior Scientist in Cell Biology at SickKids.

In 2006, three-year-old Tal (Tali) Doron was diagnosed with ATRT, a condition that makes up only three per cent of all rare brain tumours found in children. “When we found out Tali’s condition was so rare, we were frightened and felt very isolated by the lack of information available to us,” says Kim Doron, Tali’s mom and co-founder of Tali’s Fund.

“On average, SickKids sees about three to four cases of rare tumours a year, which isn’t enough to conduct a clinical trial to see significant results,” explains Huang who is also Associate Professor in the Department of Paediatrics at the University of Toronto. “By studying large numbers of patients with rare brain tumours through the RBTC, we hope to better understand the biology of rare childhood brain tumors in order to accelerate the development of new approaches to diagnosis, establish more effective therapies, and ultimately improve patient outcomes.”

Unfortunately in 2007, Tal’s cancer returned after just a few months of being home. There were no further treatment options available due to the severity of her condition and she passed away a few weeks later at the age of four. “Tali, as well as other patients and families truly inspired the creation of this registry,” says Huang.

At the time, Huang and her colleagues didn’t think a resource like the RBTC would be possible, but after more than a decade of collaborative research, the online registry was launched. “Not only will this registry benefit the research of rare brain tumours, but it will also offer a worldwide network for parents to connect with one another for moral support,” says Doron. “This resource would have helped us make more informed decisions about treatment options and given us comfort knowing we were not alone.”

To date, there are over 70 centres around the world that participate or contribute data to the registry. The RBTC facilitates dialogue between physicians around the world so they may offer support to one another and contribute data and information for research on diagnosis and treatment options. In addition, patients have easy access to reliable information and sources regarding these rare brain tumours.

“The more we know about these tumours, the better chance we have at making rare brain tumours a curable disease,” says Huang.

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Please visit the [Rare Brain Tumor Consortium](#) for more information.

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