A GLOBAL WEB-BASED REGISTRY FOR RARE PEDIATRIC BRAIN TUMOURS

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CLINICIANS have long been challenged by the treatment of malignant childhood brain tumours.

Perhaps this is most true for rare childhood brain tumours. Many of these diseases are only seen three to four times a year even in the busiest of brain tumour centres in the world which deal with over one hundred children with brain tumours annually.

Clinicians are often challenged, not only by how to treat such patients, but also how to have reliable diagnostic tools to pick out such cases. These childhood brain tumours encompass a large category of tumours collectively called CNS-PNETs, rhabdoid brain tumours and others that remain to be identified.

No clear diagnosis for some children

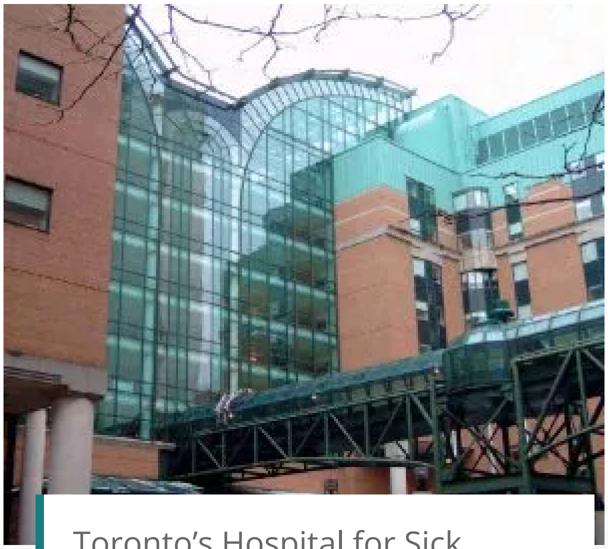
Dr Annie Huang at the Hospital for Sick Children (also known as "**SickKids**") in Toronto, Canada, started her interest in rare pediatric brain tumours as a fellow in training when she at the Arthur and Sonia Labatt Brain Tumour Research Center at SickKids, she focused on trying to advance research for these rare diseases.

With encouragement and support from her mentors, Drs Eric Bouffet and James Rutka, respective heads of the brain tumour clinical and research programs at SickKids, she started the painstaking process of building a bio-repository of rare pediatric brain tumours.


Dr Annie Huang

“It was a tedious but not a really difficult task at first as many doctors and researchers were quite happy to have someone who was interested in rare diseases and generously offered biological specimens that had been stored for many years but never studied,” Dr Huang said.

An ever-growing repository of rare pediatric brain tumours


Toronto’s Hospital for Sick Children

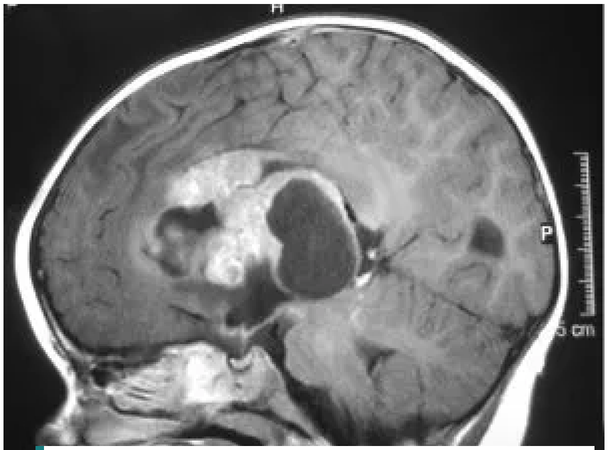
Thus over the course of the last decade and a half, Dr Huang’s collection of rare pediatric brain tumours now numbers in the hundreds – collected from collaborators and colleagues around the globe. This rare tumours bio-repository enabled early studies and discovery of diagnostic markers for a poorly recognized brain tumour of infancy.

Dr Huang said that in their first study published in 2009, they identified the same genetic marker in a group of brain tumours that were called different names, and until that point were thought to be specimens from nine different international centres, only one of which was from one of her patients at SickKids.

With the discovery of a diagnostic marker for these tumours – which is most commonly called ETANTRs but is also historically called by a number of different names – the disease is now increasingly recognized as a highly lethal form of brain tumour in very young children.

The global, web-based registry for rare pediatric brain tumours

Now investigators across the world are interested in establishing specific treatment trials for this disease, and are looking to data collected by the rare tumour network to see what type of treatment has worked for the survivors of this rare disease.



MRI of a supratentorial atypical teratoid/rhabdoid tumor (ATRT) in a young child

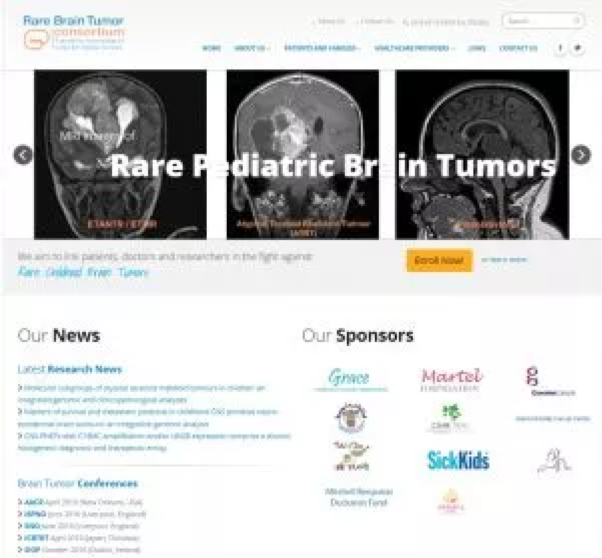
Dr Huang cites this as an example of why she and her colleagues felt it was time to launch a global web-based registry that will allow parents and clinicians from anywhere in the world to initiate the process of enrolling a child with a rare brain tumour diagnosis in this registry.

The **registry website,** which has been constructed with input and support from international clinical leaders in childhood brain tumours, will allow doctors to enter diagnostic, treatment and outcome information on their patients directly into a web-based database that will serve as a resource for future studies of other rare brain tumours not yet discovered.

In addition, the registry encourages parents and clinicians to consider submission of tissue database, I hope that the global bio-repository will serve as a valuable resource for studies of rare childhood brain tumours in many different countries."

A central hub for information and contacts

Another goal of the web-based registry is to centralize information and contacts for local experts so that parents can access reliable information and sources regarding such diseases.



"We often receive desperate phone calls or e-mails from parents from many different countries when their child is diagnosed with one of the rare brain tumours we study," Dr Huang said.

The web-based registry, she hopes, will also enable parents to seek help from more readily available local experts and be reassured that their child's management has been discussed and shared amongst the global experts in childhood brain tumours. Furthermore, as the registry is tooled up with tweets and Facebook links, Dr Huang hopes it will also become an important source of support for parents and families of children diagnosed with rare brain tumours.

Dr Huang said: "Families who have lost children to these rare brain tumours have an unrelenting passion to help others and to seek answers. They are the major driver of our efforts. Without their grassroots financial support, our study of rare brain tumours would not have been possible, as such rare diseases do not generally attract much attention from large funding agencies."

Dr Huang also credits the tremendous enthusiasm and commitment of her colleagues across

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