



Press Release

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Two Charities Team Up to Improve Outcomes for Rare Childhood Brain Cancer

Funding will fuel research to guide precision treatment for children with life-threatening brain tumours

TAMPA, FL. — How aggressive must cancer treatment be in order to achieve the best possible outcomes for children with an aggressive brain tumour called ATRT (atypical teratoid rhabdoid tumour)? An innovative research study could enable more precise and less toxic treatment for ATRTs based on each patient's response to therapy.

Brain tumours are the number one cause of death and disability due to childhood cancer. ATRT is a rare, highly malignant brain tumour that affects infants and children less than three years of age. Current ATRT treatment involves intensive chemotherapy as well as brain and spine radiotherapy which can leave these very young patients with devastating brain and organ damage.

Two charities founded by parents with firsthand experience of losing their children – Tal Doron and Zion Yamoah – to ATRTs, have come together to help researchers develop a tool that doctors can use to spare children unnecessary therapy.

[Tali's Fund](#) (Canada) and [Hope4ATRT](#) (Tampa, Florida) are teaming up to fund a promising research project led by Dr. Annie Huang, neuro-oncologist and Senior Scientist at the Arthur and Sonia Labatt Brain Tumour Research Centre at [The Hospital for Sick Children \(SickKids\)](#) on Toronto, Canada.

“We need more innovative, sensitive tools that can provide timely, dynamic information about how a patient’s disease is responding to treatment or not, so that we can adjust and tailor treatment to truly deliver precision medicine for children with ATRTs and other childhood brain cancers,” said Dr. Huang.

The study will capitalize on a SickKids-developed treatment plan called the Toronto Standard of Care Protocol, which uses chemotherapy directly delivered to the cerebrospinal fluid (CSF) to help avoid the side effects of brain and spine radiotherapy. As part of this treatment protocol, Dr. Huang has collected and banked over 100 CSF samples from patients since 2012.

The SickKids team will now employ cutting-edge technology to see if DNA shed by tumour cells in CSF can be used to predict which children can be spared radiotherapy. The researchers also hope this tool will allow them to detect treatment resistant or recurrent ATRTs early. Armed with such tools, doctors

will be able match treatment intensity and duration to an individual patient's response, making adjustments as needed to maximize effectiveness and reduce or avoid severe treatment-related toxicity from radiotherapy as well as intensive chemotherapy. Such a tool could potentially be used to monitor response to novel therapies, including immunotherapy, in the future.

"Nothing can bring back our precious children, but identifying more precise ways to individualize ATRT treatment would be a meaningful legacy for Zion, Tali and all the other children lost to this brutal disease," said Zion's parents, Dr. Kosj and Jaymi Yamoah, co-founders of Hope4ATRTR. *"Tali's Fund and Hope4ATRTR are proud to contribute to Dr. Huang's efforts."*

Kim Doron, co-founder of Tali's Fund added, *"We are excited to collaborate with Hope4ATRTR to support research that will give children with ATRT and other rare brain tumours options for treatment that simply didn't exist when Tali and Zion were diagnosed. Our goal is to help Dr. Huang and other researchers in the field make what was once incurable curable."*

About Hope4ATRTR:

Hope4ATRTR Foundation is a research entity of Out of Zion, Inc, dedicated to supporting families in the fight against ATRT with up-to-date resources and research. Our mission is to provide a centralized site where parents can find the information they need to navigate their child's diagnosis – what to do, where to go for treatment, what resources/support are available to them, and advancements through ATRT research. Learn more at www.hope4atrt.org.

About Tali's Fund:

Tali's Fund was established in loving memory of Tal Esther Doron who died at age 4 after a brave struggle with ATRT, a rare and aggressive brain tumour. Tali's Fund honours Tali's legacy by supporting research targeting safe, effective treatments for children with rare brain cancers, and collaborates globally to promote awareness of research, resources and treatments related to childhood brain cancers. Learn more at www.talisfund.org.