

Media Release 1 August 2018

WA to get its first-ever research project into brainstem glioma thanks to record \$292,000 raised at annual Brainchild Ball

\$111,255 of the total raised pledged to Sindi's Fund to kickstart research at Telethon Kids
Institute into this devastating form of childhood brain cancer

WA is set to get its first-ever research project into a devastating form of childhood brain cancer thanks to a record-breaking fund-raising effort at the recent annual BrainChild Ball at Crown Towers.

The popular event, which was attended this year by over 480 people (up from 360 last year), raised a staggering \$292,000 (up from \$210,000 last year).

The BrainChild Ball is an initiative of The Adventurers, a fund-raising charity which funds medical research to discover better treatments and ultimately a cure for childhood brain cancer.

Of the total, \$111,255 was pledged on the night to establish Sindi's Fund, named after Sindi Simic who at just 4 years of age tragically lost her two-year battle with brainstem glioma.

Sindi's mum, Dijana, delivered a moving address at the Ball in which she recounted Sindi's devastating diagnosis and the aftermath, including its massive impact on the lives of all of those around her during her brave battle against the disease.

Brainstem glioma is an aggressive and dangerous cancer which accounts for around 10 per cent of all childhood brain tumours. Around 75 per cent are diagnosed in children and young adults under the age of 20 and most commonly patients are between 4-6 years old.

Treatment is exceptionally difficult. Because the tumour is located in the brain stem, the tumour is not removed as the risks of major brain damage are too high. No chemotherapy has been found that works, and radiation therapy can only slow down the cancer growth. Survival rates are very low and there is no cure.

Professor Terry Johns, who will lead and oversee the glioma research project, is regarded as Australia's leading researcher into brainstem glioma and was recently recruited to head up the Cancer Centre at Telethon Kids Institute in Perth as part of its push to attract world-class researchers to Perth.

Adventurers Chairman Matt Fitzgerald said the Brain Tumour Research Program at the Telethon Kids Institute would make excellent use of the funds raised as the fight continued against childhood brain cancer.

"A lot has changed in the past 25 years – transformed by the digital revolution and advances in medicine and human knowledge," Mr Fitzgerald said.

"Life expectancy in developed countries has increased by a staggering 10 years. Advances with the cervical cancer vaccine, breast cancer, melanoma and many other forms of adult cancers have improved in terms of awareness, prevention, detection and, increasingly personalised treatment.

"Today, childhood leukaemia is largely curable with an over 90% survival rate – thanks to research.

"But in those same 25 years, what hasn't changed is that there has not been a single approved cancer drug developed to treat childhood brain cancer. Not one.

"This is not an acceptable situation for what is the single largest disease killer of our children, nephews and nieces, god-children and current and future grandchildren.

"Fund-raising initiatives such as this are vital if we are to find new treatment and more effective ways of treating kids who have to confront this devastating illness.

"We feel proud to have created this legacy in honour of Sindi, who was taken by this terrible disease, and I would like to thank everyone who donated, contributed, supported and helped us by being there on the night."

The BrainChild Ball, which was MC'd by media personality Tim McMillan, featured a "live" and "silent" auction, both of which saw some big-ticket items sold, including a True North Safari Cruise for \$18,000 and a painting of Sindi by speed painter and performance artist Brad Blaze for \$10,000.

100 per cent of the funds raised go to the cause. The Ball is run on a voluntary basis, with many people donating time and services to ensure the best possible outcome.

Next year's Ball will be held on 27th July at the Grand Ballroom, Crown Perth.

-Ends-



Notes to editors:

Media contact: Matt Fitzgerald, Chairman – 0438 502 859

Follow us on Twitter: @kidscancercure

FACTS ABOUT BRAIN CANCER and THE ADVENTURERS.

- Brain cancer kills more children than any other disease in Australia
- Brain tumours are the most common paediatric solid cancer, affecting 200 children in Australia each year.
- The Brain Tumour Research Program, is a collaborative group of researchers at Telethon Kids
 Institute dedicated to improving our understanding of paediatric brain tumour biology and finding
 more effective treatments to improve survival rates and quality of life for patients.
- The Pirate Ship Foundation Limited operates various for-cause activities and event, including the BrainChild Ball, The Adventurers and Pirate Day Friday in WA.
- The Adventurers have contributed over \$9.5 million to research into childhood brain cancer since we began in 2010.