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Funding breakthrough for global childhood brain cancer drug trial a globally significant step in the fight against killer disease, says Perth charity

\$4.5m in Federal Government and philanthropic funding secured for childhood brain cancer clinical trials

A major new round of Federal Government funding for rare cancer and diseases clinical trials includes \$4.5 million in funding for childhood brain cancer clinical trials. This includes funding for a major global clinical trial for a drug that was developed as a result of pioneering collaborative research in Perth largely funded by Perth-based fundraising charity, The Pirate Ship Foundation.

The clinical trial, known as SJ-ELiOT, will be led by the St Jude Children's Research Hospital, the world's biggest childhood brain cancer research centre, in Memphis Tennessee, will test a drug whose potential application was discovered as part of a drug discovery effort at the Brain Tumour Research Program at the Telethon Kids Institute in Perth.

"This is a globally significant step in the fight against childhood brain cancer and a very exciting development for everyone engaged in improving treatment options for this killer disease," said The Pirate Ship Foundation Chairman, Matthew Fitzgerald.

The trial is for children who have developed medulloblastoma, which is the most common malignant brain cancer that children can get. It will initially involve children who have relapsed with the disease who otherwise have very few, if any, viable treatment options.



The drug's potential application in childhood brain cancer treatment was discovered and developed as a result of a global collaborative research initiative in 2013 supported by what is now The Pirate Ship Foundation.

"In 2013, Clinical Associate Professor Nick Gottardo from Perth Children's Hospital and The Telethon Kid's Institute and Professor Amar Gajjar from St Jude Children's Research Hospital convened a meeting of the International Medulloblastoma Working Group in Western Australia which led to an exciting new discovery," Mr Fitzgerald said.

"The meeting brought together a team of world experts in the field of medulloblastoma, the most common brain cancer in children, and was the brainchild of the parents of a young West Australian boy Elliot, who succumbed to relapsed medulloblastoma," said Professor Gottardo.

"The meeting established a global action plan to improve outcomes for patients with medulloblastoma. Elliot's parents founded the predecessor charity to the Pirate Ship Foundation, which raised much of the funds that financed the laboratory research that led to the SJ-ELiOT clinical trial," he added.

Pre-clinical trials for the drug, which inhibits some of the protective mechanisms a cell can have when it's been damaged by chemotherapy or radiotherapy, were commenced five years ago at the Telethon Kids Institute. The promising results were shared early with international collaborators, including St Jude Children's Research Hospital, so the results could be independently validated. These characteristics of the drug mean that it interferes with the ability of the cell to repair itself, therefore making chemotherapy or radiotherapy used in the treatment of the cancer more effective.

"SJ-ELiOT is a multi-institutional collaborative trial born out of Australian preclinical laboratory research that will be conducted in three continents including Australia, USA and Europe, inspired by and named in honour of Elliot," Professor Gottardo said.

"Medulloblastoma is the most common form of childhood brain cancer and we have around 200 children with brain cancer in Australia, with over half of children dying from this disease within a couple of years of diagnosis" Mr Fitzgerald said.

"The potential benefits of this new drug are to make chemotherapy more effective – helping to cure more children on the one hand while also potentially allowing doctors to dial down the dose of damaging radiation and chemotherapy drugs.

"We've seen with other diseases such as leukaemia that survival rates have increased dramatically over the past 50 years. This is purely due to the application of clinical trials with one trial building on the next, progressively refining and improving treatments, ultimately towards a cure.



"This is a major global clinical trial of a drug to be used in the fight against childhood brain cancer and it's incredibly exciting that this Government funding has come about because of the pioneering work of the Telethon Kids Institute in Perth.

"I would like all of our supporters and friends to know that this outstanding progress is a direct outcome of their philanthropic efforts and generosity – our grants have backed quality research and global collaboration, leading to the discovery of this drug."

About The Pirate Ship Foundation

The Pirate Ship Foundation last year granted \$400,000 to the childhood brain cancer research programs at Telethon Kids Institute for 2019.

The outstanding result – which was based on a range of innovative community based fund-raising events and activities throughout 2018 – will support the 2019 Brain Tumour Research Program at Telethon Kids Institute, helping to fund world-leading research teams led by Professor Terry Johns, Associate Professor Nick Gottardo and Dr Raelene Endersby.

The Brain Tumour Research Laboratory, which is co-headed by Clinical Associate Professor Gottardo and Dr Endersby, is a collaborative research team focused on improving treatments and outcomes for children with childhood brain cancer. The team is the largest of its kind in Australia, and includes dedicated research scientists, clinical oncologists and neurosurgeons.

The Pirate Ship Foundation brings together an extensive range of bold and innovative fund-raising efforts, supporters and community under one banner.

The Pirate Ship Foundation is aiming to build on the outstanding work and achievements of its past activities by launching a series of new events to run alongside its existing fundraising initiatives such as The Adventurers programs, primary school-based Pirate Day and The BrainChild Ball.

Some of the upcoming events include:

- A new Walk the Plank! event to be held at HBF Stadium which will see highprofile CEO's and business leaders nominated by their staff (crews) to take the plunge off diving boards of increasing heights (planks) in front of a live audience;
- Pirate Day, held nationally across May in partnership with The Kids Cancer Project;
- Four new 2019 Adventure team challenges across Australia; and
- The annual BrainChild Ball, to be held at Crown Perth on 27 July 2019.



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Notes to editors:

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FACTS ABOUT BRAIN CANCER and THE PIRATE SHIP FOUNDATION.

- 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 in Perth 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 events, including the BrainChild Ball, Walk the Plank, The Adventurers and Pirate Day.
- The Foundation has contributed over \$7 million to research and collaboration into childhood brain cancer in WA.



¹ The Federal Government will invest \$2.9 million with an additional \$1.6 being contributed by Carrie's Beanies 4 Brain Cancer and the Mark Hughes Foundation through the Government's Australian Brain Cancer Mission.