# BRAVE PARENTS JOIN FORCES TO BATTLE FATAL BRAINSTEM TUMOUR

A fight for the kids

A DEADLY brainstem tumour with a survival rate of zero will be given a funding boost by four Victorian parents determined to stop it in its tracks.

After losing their children, Isabella and Marcus, this inspirational foursome are dedicating their lives to raising money to find a treatment for the Diffuse Intrinsic Pontine Glioma (DIPG).

The charity has raised more than \$500,000 and is already directly funding three research projects in Melbourne.

"Our ultimate goal is that a family diagnosed with DIPG is given some hope, some kind of treatment to prolong their lives or save them," Daniela Ruberto said. "Currently, there is nothing that you can do, your child becomes paralysed, they don't eat, they don't drink and they can have radiation but it's usually only palliative care."

Mrs Ruberto recalls the day she had to tell her five-year-old son, Marcus, he was dying.

"Marcus looked at me and said: 'What's wrong with me, Mum?'

"I told him he was really sick there was something horrible growing in his brain, a tumour,

#### **LUCIE VAN DEN BERG**

which is why he was walking and talking funny.

"I said, there is no medicine for you and you are going to die and be with Jesus and the angels; they'll look after you."

Marcus, the child she and her husband had taken 11 years to conceive, turned to her and said: "I know what's in the angels' wings—lollies."

After his death the Rubertos met Khush and Robert De Rose, Isabella's parents, and they formed a foundation named in honour of their children — The Isabella and Marcus Paediatric Brainstem Tumour Fund.

Shocked by the lack of medical research being carried out into DIPG, which claims 90 per cent of diagnosed children's lives within 18 months, they vowed to donate their funds straight to the institutes.

Monash Institute of Medical Research-Prince Henry's Institute Dr Jason Cain, whose work has been funded by the foundation, said it was extremely difficult to get funding for rare paediatric cancer.

ISABELLAANDMARCUSFUND.ORG.AU lucie.vandenberg@news.com.au





## PROJECTS FUNDED BY THE ISABELLA AND MARCUS FUND

#### Murdoch Childrens Research Institute

■ Developing genetically engineered mice to recapitulate paediatric brainstem tumours — specifically DIPG — in mice to develop new treatments.

### Monash Institute of Medical Research-Prince Henry's Institute

■ Developing alternative models of DIPG. For example, they will develop new cell lines from primary human brain tumour donated from children

that have died from DIPG to see how these cells subsequently become cancerous.

#### **Monash University**

- Examining mutations found in DIPG and how they affect the replication of DNA, which goes awry in cancer.
- Two PhD scholarships will be awarded in 2014 thanks to funding from The Upstream Foundation. Each scholarship named in honour of a child that died from DIPG.



Clockwise from left: Isabella de Rose; Marcus Ruberto; Tony and Daniela Ruberto (Marcus's parents) and Khush and Robert De Rose (Isabella's parents).





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