The Sydney Morning Herald

POLITICS FEDERAL BRAIN CANCER

Grieving father pushing for son's legacy to live on through rare cancer research

By Rob Harris

October 23, 2019 - 7.03pm



A grieving father is pushing for his son's legacy to be remembered through a world-leading Australian brain cancer research centre.

Tasmanian Jack Fleming died in April last year from an incurable brain tumour, just months after celebrating his 21st birthday.



Health Minister Greg Hunt with Ken Fleming, who has written a book about his son Jack, who died of a brain tumor. DOMINIC LORRIMER

His dad, Ken Fleming, kept a daily diary of his son's struggle and promised his son he would aim to raise \$1 million from the sales, sharing his story of the "rotten disease" with the world.

Jack's Story, details his father's heartbreaking account of his son's diagnosis and eventual death from glioblastoma multiforme - the most aggressive and deadly

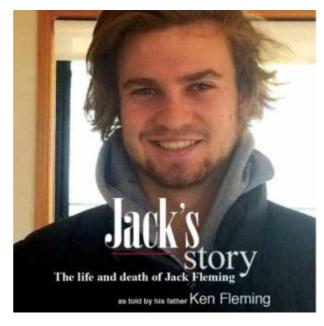
form of brain cancer.

"The horrific death Jack went through at the prime of his life is something that no family should have to experience," Mr Fleming said in Canberra on Wednesday.

"The death is painful and takes the lives of ... too many children."

"I made a promise to Jack that I would tell his story and initially we hoped it would be about his fight and survival. But it wasn't to be."

Mr Fleming is now working with doctors and medical researchers at NSW Health, the Royal Prince Alfred Hospital and the University of Sydney



The cover of Ken Fleming's book.

to establish a National Centre for Brain Tumour Neuropathology - to be known as the Jack Fleming Centre.

It will undertake a number of research initiatives, including replacing brain tumour biopsies with a simple blood test, understanding how tumours become resistant to treatment and develop novel therapies such as gene-editing of the brain's defence cells, the microglia.

Mr Fleming met with Federal Health Minister Greg Hunt, who said he was moved to tears on reading the account and phoned Jack's dad to offer help.

"It seemed to have struck a chord. He called me the day he received the book and we have been talking ever since," Mr Fleming said.

On average, about 1750 brain cancers are diagnosed each year in Australia and survival rates remain low despite significant increases for Australians diagnosed with other types of cancer, such as prostate and breast cancer.

"[Jack] gave life ... his best shot," Mr Fleming said. "He never stopped smiling; he never gave up; never said no more."



Ken Fleming promised his son he would share his tragic story of brain cancer. DOMINIC LORRIMER

He said writing the book had helped his grieving process but said his wife, Dianne,

had found it too hard to read.

Mr Hunt said he had felt "the immense pain of a dad who had lost his son" after reading the book.

"There is something about paediatric and adolescent brain cancer that tears at the fabric of all of us, because parents see their children fade before their eyes," Mr Hunt said.

"Australia has the highest rate of brain cancer survival, but it's still only 22 per cent, which means we need new treatments, immunotherapies and powerful advocates such as Ken.

Jack's Story, by Ken Fleming, is published by Forty South Publishing, rrp \$39.95. Visit jacksstory.com.au



Rob Harris







Rob Harris is the National Affairs Editor for The Sydney Morning Herald and The Age, based at Parliament House in Canberra