Dainere's Legacy

Dainere was the most courageous, selfless and inspiring young person you could ever meet, she worked passionately and tirelessly during her short life to raise awareness and funds for childhood brain cancer. Her greatest wish in life was that no child in the future would have to suffer as she did and that one day a cure for this horrendous disease will be found.

Dainere was a prolific awareness and fund raiser for childhood brain cancer and an inspiration and role model at School and in the sporting arena. She is a twice published author, has an asteroid and Street named after her and was posthumously named as The Young Canberra Citizen of the Year 2013 jointly with Jarrett in recognition of their leadership, courage, and determination to raise awareness in the Community of childhood brain cancer.

About Dainere's Rainbow Fund

Our Mission

Dainere's Rainbow are dedicated to elevating vital awareness raising funds, advocacy and initiatives to improve outcomes for every child in Canberra and around Australia 0-19 diagnosed with childhood brain cancer.

Our Vision

One hundred percent cure rate for all children diagnosed with brain cancer, through Australian research.

Dainere's Rainbow was established in February 2014 with the objective to Take Action, Bring Hope and Create Change for children diagnosed with brain cancer supporting Sydney Children's Hospitals Foundation and the world class childhood brain cancer research projects and programs of Professor David Ziegler, set up in memory of and a legacy to Dainere.

Professor Ziegler and his team are working towards the implementation of novel treatment strategies, state of the art clinical trials, safer treatment options with less devastating side effects and ultimately a cure.

Dainere's Rainbow is run entirely by family and a dedicated team of volunteers which means that **100% of all funds raised or donated** go directly to this vital research at the Sydney Children's Hospital, Kids Cancer Centre.

Maintaining a lifetime commitment to working towards dramatically increasing awareness, raising vital funds and the eradication of this insidious disease, whilst providing practical and knowledgeable non-medical support to others, which was Dainere's ultimate wish.

Awareness, Fundraising and Initiatives

A Small Selection Of Our Achievements

Annual Events

- Gala Dinner Event
- City2Surf
- Christmas Light Display
- Dainere's Rainbow Run (Burgmann Anglican School)
- Andante Andante ABBA Choir Event

Initiatives

- Campaigning and collaboration for Paediatric Palliative Care Nurse in Canberra
- Collaboration for By My Side Bereavement Resource
- Panel for Creating the Role of Paediatric Palliative Care Nurse
- Childhood Cancer Awareness Month Campaign
- Unmasking Grief video series
- Collaboration and Consultation for Planning Child's Funeral Resource
- Consultation for the Paediatric Palliative Care National Action Plan

Awareness

- Family Support and Information on website
- Qcity Transit Awareness Raising Bus Campaign 2017-2022
- Children's Activity Booklet
- A Sibling's Perspective Paedriatric Palliative Care
- Symptom Awarness Campaign
- The Inside Story Video
- Attendance at Numerous Community Events
- Various News Articles

Every child deserves a chance of a future and it is only through vital Community support that crucial research projects and programs can be undertaken to offer new hope and the best chance of cure with minimal treatment side effects for future generations of Australian children and their families.

- Professor David Ziegler

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This brochure was produced by

Jarrett Anthoney
Young Canberra Citizen of the Year 2013
ACT Finalist Young Australian of the Year 2015
7NEWS Young Achiever Awards NSW/ACT Finalist 2020



CHILDHOOD BRAIN CANCER

Awarness, fundraising, advocacy, connecting, support and initiatives to offer new hope and a future

BRAIN CANCER KILLS MORE CHILDREN THAN ANY OTHER DISEASE IN AUSTRALIA

(Australian Bureau of Statistics, 2010-2021)

"My little voice could only make a small difference, but together many voices could create change"



Dainere 1998-2013





"I think there is nothing more cruel or unjust in this world than to see a child die at a young age from an incurable disease. It remains a sad and devastating fact that brain tumours, as a group, are the number one disease causing the most deaths in childhood. Dainere was truly selfless and inspiring, and her family through Dainere's Rainbow now devotedly continue her legacy to help us bring new hope to future generations."

- Professor David Ziegler Kids Cancer Centre Sydney Children's Hospital

Key factors to consider...

- Research offers the only hope of dramatic improvements and outcomes for children diagnosed with brain cancer.
- The needs of children with brain cancer in treatment, rehabilitation and end of life care are very different and particularly acute.
- Detection and treatment of childhood brain cancer is often critically delayed as symptoms are broad and often confused with less serious illness.
- There are no known causes or lifestyle changes to prevent children from getting brain cancer, making early screening, or testing unrealistic.



Facts and statistics about Brain Cancer

- Brain cancer is the most common form of solid tumour among children.
- Brain cancer kills more children in Australia than any other disease (Australian Cancer Registry 2021).
- Brain cancer has the highest total burden of disease for children and adolescents in Australia, with a cost of \$1.7 million per person (CanTeen Australia 2017, The economic cost of cancer in children adolescents).
- On average approximately 2000 brain cancers are diagnosed each year in Australia and over 1500 deaths, this means that six people are diagnosed every day and four will die (AIHW 2021).
- Alarmingly there have been significantly increasing trends in incidence rates of Medulloblastoma, a shocking 58% increase over a thirty-five-year period (Australian Childhood Cancer Registry, 2020).

Symptoms of a Childhood Brain Cancer:

- Persistent or recurrent vomiting often on waking
- Abnormal or poor balance
- Wobbly or gaited walk
- Poor co-ordination
- Unexplained weight loss or gain
- Behaviour change
- Fits or seizures
- Abnormal eye movements and blurred or double vision
- Lethargy
- Abnormal head position such as a head tilt or stiff neck
- Delayed or arrested puberty in adolescents
- Reduced consciousness
- Diabetes insipidus (excessive drinking and urination)
- Frequent flu like symptoms
- Decline in school performance
- Loss of bowel or bladder control



Challenges of Childhood Brain Cancer Treatment

- Treatment of childhood brain cancer is more complex than that for other childhood cancers.
- Brain cancer surgery when accessible, requires a highly skilled team of health professionals to safely remove as much of the tumour as possible while avoiding damage to normal tissue essential for brain function.
- Chemotherapy used to treat brain cancer is restricted to a small number of drugs that can cross the blood-brain barrier.
- Radiotherapy treatment requires careful and accurate planning and precision to avoid damage to normal brain tissue.
- Children in Canberra and surrounds diagnosed with brain cancer are not able to be treated here, they are transferred to the Sydney Children's Hospital Network for surgery and all treatment.

How Can You Create Change?

- Be proactive using social media and verbal communication to elevate crucial awareness in the Community.
- Make a once off or regular donation to a fund like Dainere's Rainbow where 100% of all funds raised go towards research and other programs to support childhood brain cancer
- Email your Local Government MLA and your representative within the Federal Government asking them to support awareness and funding to be directed to childhood brain cancer research.
- You are welcome to contact us if you would like to volunteer at a Dainere's Rainbow Event.
- If you are a Business Owner please consider making a donation of goods or services for auctions/raffle prizes or join the Dainere's Rainbow Team as a Partner for one of our fundraising events.

