RARE CANCER CARE AND RESEARCH FUND



WHAT IS THE RARE CANCER CARE AND RESEARCH FUND?

Help provide patient-centred care initiatives that advance the provision of care for people with rare forms of cancer.

The Rare Cancer Care and Research Fund (RCC&RF) was established in October 2022 through the generosity and foresight of two patients of the Sunshine Coast Hospital and Health Service - Melissa Evans and Neil Russell.

It operates under the auspice of Wishlist (Sunshine Coast Health Foundation) in collaboration with Sunshine Coast University Hospital (SCUH), particularly the Medical Oncology Unit and the Research Governance and Development Unit. Collaborations are also being progressed with key external parties including Cancer Alliance Queensland and Australian Families 4 Genomics. Wishlist is acting as custodian of donations to this Fund, with an emphasis on the principles of good governance, patient focus and respect for donor intention.

Donations to the Fund will be best used for patient-centred initiatives that advance the provision of care for people on the Sunshine Coast experiencing rare forms of cancer. Funds will not be applied to initiatives for those forms of cancer for which significant government and private funding is already available.



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ADEM CROSBY CENTRE

Australian Families 4 Genomics

WHY GET INVOLVED?

HOW DO RARE CANCERS DIFFER?

- Rare cancers affect approx. 5000 Queenslanders each year.
- The most common rare cancers are some bone marrow cancers, mouth and gallbladder.
- More men are diagnosed with a rare cancer than women.
- Only half of all people with a rare cancer survive 5 years.
- Continued efforts are needed to understand and address the impact on people diagnosed with rare cancer in Queensland.

MAKING A DIFFERENCE

The RCC&RF will practically assist people with rare cancer and their treating specialists in a variety of ways, including:

- Highlighting the unique needs of people with rare cancer.
- Progressing formal research projects.
- Genomic sequencing.
- Using data to help inform patient care.
- Generating data for future research.
- · Accelerating scientific discovery.

HOW YOUR SUPPORT CHANGES LIVES

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Martha's Cancer Journey



Those waging personal wars inspire others

IT'S EARLY DAYS, HOWEVER THE RCCRF HAS ALREADY BEEN SUCCESSFUL IN:

- **Preparing research-ready data** that was presented at the Clinical Oncology Society of Australasia (COSA) annual scientific meeting in November 2023.
- Funding Genomic Testing for patients diagnosed with rare cancer on the Sunshine Coast as part of provision of care.
- Partnering with the Australian Rare Cancer (ARC) portal to fund a research fellow part-time who is now working at SCUH to provide rare cancer advice and information to oncologists to help manage QLD patients, especially those from rural and regional areas.
- **Building relationships** with surgeons and radiation oncologists in QLD who are interested in collaborating and specifically looking at outcomes for SNUC and other rare cancers.
- **Collaborating with ARC** and other partners around the state to explore the creation of a Sino Nasal Undifferentiated Carcinoma (SNUC) database and further research.
- **Raising awareness of SNUC** and also increasing research into this rare cancer.





TESTIMONIALS

It is my greatest hope that through the establishment of this fund future generations will not have to experience the heartbreak of being diagnosed with incurable cancer and that along that journey there is more care available to people diagnosed with life changing rare cancer.

> *Melissa,* Co-founder of RRCRF

I am 74 years old and keep asking why so many young people are being diagnosed with cancer? Support is needed to research what we can be doing as an educated community to understand and change this.

> *Neil, Co-founder of RRCRF*

Giving to the RCC + RF will help to ensure that patients on the Sunshine Coast, with rare forms of cancer have equity of access to research, treatment options and supportive care.

> Ebony, Oncology Clinic Nurse Consultant



I'm incredibly humbled by the generosity of our founding patients and families to help set up this fund. We are working hard to fulfil their wishes and use the funds wisely to accelerate the care and research into rarer cancers. We already have accessed funds to cover the cost of comprehensive genomic testing for people with rare cancers here on the Sunshine Coast. In addition, new research collaborations with key partners will deliver a better understanding of the epidemiology and treatment patterns of people with rare cancers in Queensland. Ultimately, my wish is that the fund continues to grow and that our initiatives and research will improve the care and outcomes for people affected by rare cancers on the Sunshine Coast.

A/Prof Bryan Chan Medical Oncologist, SCUH

DONATE TO THE RARE CANCER CARE AND RESEARCH FUND

Donations to this Fund can be made at any time via:

Wishlist Fundraising, Bank of Queensland BSB: 124 042 Account: 228 070 86 Please assist by referencing your name and RCC&RF.

OR

Donate online <u>here</u> or via the QR code below







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