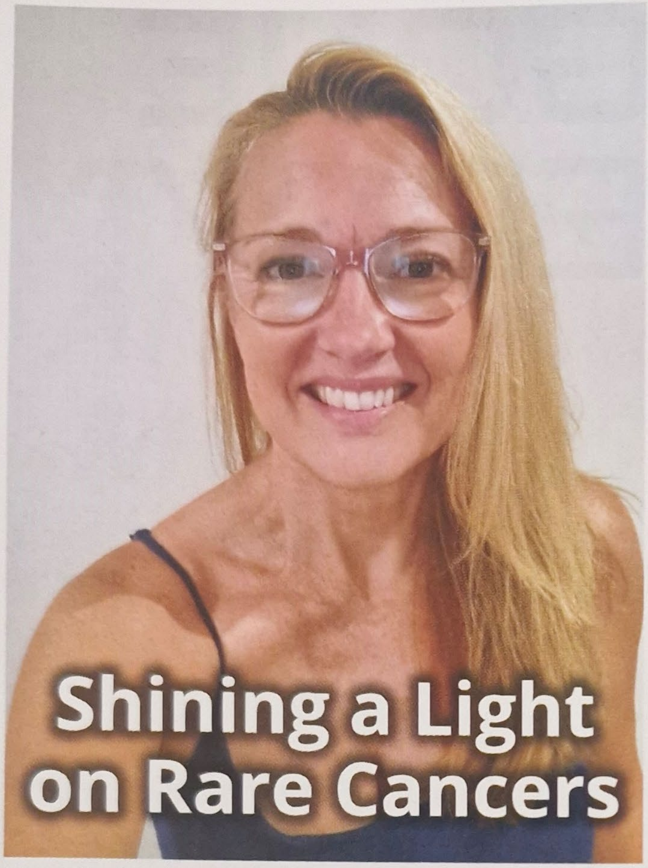
Shining a Light on Rare Cancers



Dee Clark

STORY **BROOKE JACOBSON**

Dee Clark has learned how to turn grief into advocacy.

After losing her brother to a rare form of cancer in 2005 and then dealing with her own diagnosis for the same cancer, Dee is on a mission to help raise awareness about neuroendocrine cancers, known as NETS.

"These are rare cancers, and a lot of doctors just don't have the information about NETS," she said.

"NETS can mimic other cancers, and other conditions, including anxiety, irritable bowel syndrome, and even menopause, so a lot of patients are not being diagnosed, they're falling through the cracks."

Neuroendocrine Cancers are a complex group of tumours that develop predominantly in the digestive or respiratory tracts but can occur in other areas of the body. The tumours arise from neuroendocrine cells.

When caught early, NET cancers can often be cured with surgery. Unfortunately, many patients are diagnosed too late.

"On average, it takes about five years to get a diagnosis," Dee said. "NETS can cause an increase in blood pressure and heart rate, so much so that it causes a heart attack.

"A lot of the time, patients present to the emergency department and staff don't know what they're being presented with. You can end up being treated for a heart attack, but that treatment could kill you."

To raise awareness and badly needed funds for research, Dee is organising a local March4NETS at the Shorncliffe Pier.

"March4NETS is a national event," Dee said. "It's about patients and their families connecting, supporting each other, and raising awareness of this disease.

"Anyone can come along and join in, buy a sausage from the BBQ or a raffle ticket. We want to be raising awareness about this in a fun way."

Dee added that NETS was only rare "until it happened to you".

"My brother Scott was 42 when he died in 2005 and back then very little was known," she said.

"And even now, there's still so little known about it because there is not enough funding for research. And without awareness, medical researchers won't get that funding.

"My NETS is now under surveillance, so I have regular PET scans and blood tests; it's always in the back of your mind.

"I feel in Australia we have great cancer advocacy and great treatments, but not enough for rare cancers, so I'm campaigning for equity in treatment."

To find out more, go to **neuroendocrine.org.au**

Dee's late brother, Scott

MARCH4NETS
Sunday, 8 March, 10am
Shorncliffe Pier
Park Parade, Shorncliffe.