

Why is it in Australia's interest to have a viable, internationally competitive health and medical research sector?

This submission is written from a personal perspective, as a person who has watched two loved ones die at a young age, after a prolonged fight with disease.

Mark Parrilla was my husband and had just turned 27 when he was diagnosed with Chronic Myeloid Leukemia (CML) in 1992. He was extremely fit, very well educated, and highly intelligent. Long term survival of CML was about 30% at the time. We got married that year, and both of us believed he could 'beat it'. Interferon at that time was touted as the new wonder drug, and Mark was undergoing therapy of interferon and another chemotherapy (Ara-C). After a year with insufficient improvement in the bone marrow tests, Mark agreed to trial taking very high doses of interferon. The cost of the drug was very high, and Mark administered it to himself twice a day. Mark said it was like giving yourself the flu every day as interferon is what the body's immune system produces when you have a virus. The trial went for a year, and was unsuccessful, and was discontinued.

In 1996 Mark's leukemia transformed into the acute phase, and he was given a match unrelated bone marrow transplant. He survived 3 days short of a year post transplant, dying at age 32 from transplant complications (graft versus host disease).

Mark's specialists at the time said the disease would be cured in the next 15 years, and indeed a few years after Mark died the drug Gleevec came along to assist treating CML, increasing long term survival to 95%. Now new treatment regimes will surpass Gleevec.

Mark was a research electrical engineer, and being able to participate in a clinical trial not only gave us and our families hope, but made Mark feel he was still able to do something to advance research for a treatment, even if it did not work. I believe that was something he 'hung onto' in the end adding to his sense of purposes for suffering.

In May 2005 my eldest brother, Peter Foley, then aged 51, was finally diagnosed with a football-sized tumour in his chest cavity. It was an extremely rare kind of cancer called a thymoma, a cancer of the thymus gland. The tumour was removed and he was given the all clear. In late 2007, Peter's health was declining and doctors found that the cancer had moved to the lining of his chest wall. Peter was deemed inoperable and terminal. He was given about 3 months to live.

My family scoured international research and alternative medicines, and an alternative treatment called Zeolite seemed to help. Later Peter had radiotherapy to reduce pain and to potentially prolong life. He bravely battled on for three more years, and saw his daughter finish high school and complete her first year of university. He also managed to celebrate his 30th wedding anniversary. In

2009, when he could have no more traditional radiotherapy without damaging major organs, Peter decided to go overseas to get a new form of radiotherapy called Tomo-therapy. It was not yet available in Australia. Peter and his wife went to Hong Kong the day after his daughter's last HSC exam, to be treated for a month in Hong Kong. The treatment cost Peter \$35,000. It helped sustain Peter another year, and he died on 29 December, 2010.

The points I want to raise about health and medical research in Australia is not one of economics, but of people and humanity. I am aware that spending money on treating some people who are inevitably going to die might be better spent on 10 hip replacements. But I think a few points are worth making.

- 1) Being able to participate in clinical trials can give ill Australian's and their families hope and a sense of purpose and contribution, even if the treatment does not work.
- 2) Where newer methodologies and treatments are developed overseas, such as tomo-therapy, it takes greater time to come to Australia. If not developed here or trialed here, we may further delay getting the treatment as we do not have the human resources adequately trained in using the new regime. (I understand tomo-therapy is now available at the Peter MacCallum Cancer Centre in Melbourne).
- 3) In the absence of anything else, Australians will look at alternative therapies. Yet there is little research into complementary medicine, while most Australians indulge in them, be it only a multi vitamin.

As a modern, advanced economy, if Australia can afford to have its own world-class health and medical research sector, it should have one, and in that way, improve the quality of life and wellbeing of all its citizens, especially those who are sick now.

Elizabeth Foley