

From: [Angela Wicks](#)
To: CommentsMSAC@Health.gov.au
Cc: [Peter Orchard](#)
Subject: RE: MSAC Application - 1748 - Canteen
Date: Friday, 9 June 2023 4:06:00 PM
Attachments: [image002.png](#)
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Dear [REDACTED]

Thank you for the opportunity to provide input to the review of Tisagenlecleucel for treatment of confirmed relapsed/refractory CD19-positive acute lymphoblastic leukaemia in children and young adults up to 25 years old.

At Canteen, young people (aged 12-25) are at the centre of everything we do. We provide counselling and psychology services, individualised support, and youth-friendly resources help young people develop skills and resilience to cope with cancer. We also support parents of young people through their cancer diagnosis with expert advice, counselling and connection to other parents in similar situations, because when parents have the skills and support to cope better with cancer and communicate openly, their children cope better too..

We are experts in what matters most to young people who are going through cancer and therefore represent the patient perspective in relation to this review. We wish to submit Joe's story (attached) for consideration by the MSAC. Joe is his real name, and he has consented for his name to be used, shared and published, but he is also understanding that you may need to change or remove his name in accordance with your privacy policy.

Joe's story is an example of the stories we see every day at Canteen and demonstrates the benefits of this treatment for young cancer patients. It highlights that the things that matter most to young cancer patients are having enough health and energy to engage with life and be 'normal' throughout treatment. For young people, being 'normal' includes working or studying, maintaining friendships, pursuing hobbies and passions, and making meaningful contributions such as through fundraising, volunteering and advocacy.

More information about Canteen and the work we do can be found at www.canteen.org.au.

Kind regards

Angela Wicks (she/her)
Policy & Advocacy Manager

Joe's story

Joe is a remarkable young man, he is a musician, teacher, scientist, youth cancer advocate, dancer and nature lover. He also has acute lymphoblastic leukaemia.

Joe's cancer was initially treated with chemotherapy and radiation therapy, and he underwent a failed transplant. Throughout these treatments he endured the harsh and debilitating side effects of traditional cancer treatments such as hair loss, toxic reactions, profound chronic fatigue, vomiting, and weight loss.

Two years ago, Joe was given the opportunity to try CAR-T (Chimeric Antigen Receptor T-cell) therapy. He received two rounds of the treatment funded through compassionate access. For Joe, CAR-T has not given him the long-term remission he had hoped for, however his story highlights the benefits and human aspect of this innovative therapy.

The CAR-T therapeutic process, involves harvesting, modifying, expanding and re-infusing a patient's own immune T-cells, to target and destroy certain cancerous cells. The specificity of CAR-T therapy targeting cancer cells minimises the negative effects on healthy cells. It is therefore far less burdensome for the patient and provides significantly improved quality of life compared to traditional cancer treatments, because the side effects are considerably reduced—no hair loss, no chemo toxicity, less fatigue, no vomiting, and no weight loss.

The impact of CAR-T therapy on Joe's quality of life cannot be understated. Even though the treatment ultimately did not lead to long-term remission, it provided him with several months of decent quality of life. CAR-T has given Joe enough health and energy to maintain independence, work as a cardiac scientist, violin teacher and youth cancer advocate, pursue his passions and hobbies such as music, dancing and camping and retain his identity despite the challenges he faced.

While the cost of the treatment is substantial, the benefits are priceless. The months of enhanced quality of life, the ability to engage in meaningful activities, and the precious moments shared with loved ones are invaluable and cannot be measured solely by monetary value.

Although the therapy did not result in a long-term cure for Joe, he strongly believes that even when it doesn't work, the treatment is worth it.

Joe's experience serves as a testament to the potential benefits and positive impact this innovative treatment can have on patients' lives. Through reduced side effects, improved quality of life, and the opportunity to continue pursuing personal and professional goals, CAR-T therapy has the power to transform the lives of patients, even in the face of adversity.