

Te Aho o Te Kahu Consumer Reference Group Members

Brian Sheppard

I had surgery and radiotherapy in 2003 for cancer in my tongue. This led me to be a Cancer Connect telephone volunteer for the Cancer Society and a consumer representative for the Central Cancer Network (CCN). I have served on many CCN working groups including Cancer Consumers New Zealand (CCNZ) and faster cancer treatment planning for head and neck cancers.

I am mindful of inequities experienced by Māori, Pacifica, people who are remote from large cities and others whose every-day life challenges make it difficult to benefit from the health services available to other Kiwis. I ensure that these considerations are taken into account in discussions about cancer support services.

Christine Sapwell

Tēnā koutou katoa, ko Christine Sapwell tōku ingoa, nō Te Tai Tokerau ahau.

Greetings, my name is Chris Sapwell and I am proudly from beautiful Northland. I am of Ngā Puhi and Ngāti Manu descent. I am a very proud wife and mama and we are privileged to have a wonderful whānau of friends. I participate in and serve my community in many ways including governance and trusteeship roles.

I have been a registered nurse for over 30 years with a special interest in primary, community and child health. I am a nurse educator with a Master's Degree in Health Sciences and teach on the Bachelor of Nursing Programme at North Tec with an emphasis on improving equity and health outcomes and growing and inspiring our nursing workforce. I have worked in health management, community and occupational health, quality improvement and health education in Northland for 20 years and have a broad range of practical health experience.

Our whanau has a business in Whangarei focusing on health and wellness of which I am a Director. I am currently on a journey of recovery from breast cancer diagnosed in 2019 and look forward to using my insights from both my own interactions with health services and my expertise and experience to improve cancer experiences and outcomes for whānau.

Diana Ayling

I am the Chair of the Head and Neck Cancer Support Network. In my role as Chair I am focused on creating a collaborative space to support the improvement of treatment, care and support of those affected by head and neck cancer. I have experience in law,

education, and not for profit organisations. I am experienced in using information and communication technologies to support organisational goals. My previous work has included supporting Māori organisations and individuals to achieve their goals. I am driven by a desire to ensure cancer patients received the best possible services.

Heather Browning

I have spent most of my professional life working in disability and health services. So, while I have come to understand the health system, I was not at all well prepared for my own cancer journey some years ago. Neither could I have prepared myself or my daughter for the recent loss of all three of my three brothers, her uncles. They each died from different cancer diagnoses within two years of each other. Our respective journeys with each of them allowed us some valuable insights into what works well, and what could be improved to better serve people and their whānau affected by cancer in Aotearoa. While it was a harrowing period in our lives it was also a time for much love and reflection. I now feel very privileged to be working alongside other members of this group, to give voice to the experiences of my whānau, knowing that each of my brothers will be contributing to this valuable work.

Henare Kani

Piki atu au ki te tihi o taku maunga Raikatia ka titiro whakararo ki ngā ripo wai o Mangapuaka me ngā hiwi o te papakainga ko Ngāpaeruru e. Tini whetu ki te rangi ko Rangitāne ki te whenua ko Henare Kani ahau, tihei mauri ora.

I live in Dannevirke and from a rural whānau and have spent a lifetime among my people of Rangitāne and Ngāti Kahungunu and totally committed to the wellbeing of my people and my community. I am married to Tungāne and support the aspirations of our whānau, hapū and iwi. Tēnā koutou katoa.

Jo Stafford

I am a survivor of testicular cancer and today I use the experience of my 'journey' to assist whānau experiencing cancer inside our health system, walking alongside them as their advocate.

My experience also assists me in advising several health organisations on how to design equity-first services and I also provide advice to private health and primary care practices.

My professional background is in designing and leading brand-led cultures for SME's drawing on Te Ao Māori through my brand agency - Colour.

Married, I have twin boys who have been raised in since birth and continue to thrive in rūmaki.

John MacDonald

I am a Queenstown Lakes District Councillor, the Independent Chair of Southern Mental Health and Addictions, Network Leadership Group and Chair of South Island Cancer Consumer Group.

I have spent most of my career involved in farming, adventure tourism, marketing, publishing, and motor trade in Queenstown before a cancer diagnosis led to a change in direction. Following a difficult 18-month period to be diagnosed, I took surviving cancer as an opportunity to deliberately redirect my life.

I sold my businesses and drew on my skills and new connections in the health sector to take on roles that span integrating mental health and addictions services, local government, community development, and cancer service improvement.

I am committed to ensuring the consumer voice is heard in health services.

Leilani Jackson

Talofa lava

I am a Samoa-trained nurse and a Fiji-trained physiotherapist, and my early health work experience in the islands has helped me appreciate working in low resourced health areas. I believe I bring a strong knowledge and experience base to improve cancer outcomes for people living with cancer, their service providers and communities.

I have led, supported or influenced programmes and responses across a number of Pacific Islands. I migrated to New Zealand in 2009 and quickly learnt the challenges of Pacific Islanders accessing health services. I also learnt the challenges of the services to engage with Pacific Islanders.

My work as a Cancer Nurse Coordinator for Pacific peoples in Counties Manukau Health provided me the platform to address cancer from an individual through to familial and a community level. My work and engagement with peoples and communities are based around the understanding of "nothing about us without us!"

Libby Burgess

I am Chair of the Breast Cancer Aotearoa Coalition, a consumer-based charity which supports, informs and represents New Zealanders with breast cancer and acts as an umbrella group linking to over 30 other breast cancer support groups and charities.

I am a consumer representative on the Breast Special Interest Group of Cancer Specialists and an affiliate member of Breast Cancer Trials (Australia and NZ).

I helped to develop NZ's Best Practice Guideline for the Management of Early Breast Cancer and Standards of Service Provision for Breast Cancer Patients. I have actively campaigned on a range of issues, including the need for timely provision of cancer treatments, better access to medicines and action to overcome inequities for Māori and Pasifika with breast cancer.

I had breast cancer when I was 41 and am committed to supporting others through their cancer experiences and working to achieve optimal outcomes for patients. I was made a Member of the NZ Order of Merit in the 2011 New Year's Honours list for services to women's health.

Marj Allan

I live in Pegasus just a small town just out of Christchurch. Cancer has been part of my life for the last 20 years, my cancer is Multi Myeloma. I have been involved as a Cancer Consumer for many years, I owned my own business and through this I believe I can bring great organisational and practical skills to the table. After working nationally with many groups, it has become very apparent cancer diagnoses and treatment has to be a big focus of the health system.

I look forward to working with the group to support the Cancer Agency and the people of New Zealand.

Mary Bradley

Kia ora, I'm the Communications Manager and a founding member of Bowel Cancer New Zealand: a nationwide, patient-focused charity dedicated to reducing the impact of bowel cancer in our communities.

Over the past ten years I've worked hard to support people affected by bowel cancer, co-ordinated awareness and education campaigns - while raising three boys.

During this time, I've advocated strongly for a nationwide bowel screening programme, which is now being rolled out across NZ; set up an online support group for patients, and last year fronted a nationwide awareness campaign 'Bowel Cancer Can Affect Us All'.

I was diagnosed with stage 3 bowel cancer in 2007 when I was aged 28 and had a six-month-old baby. My experience highlights that you're never too young to get bowel cancer. My father is also a bowel cancer survivor and we both have Lynch Syndrome; a rare inherited condition that increases the risk of getting bowel cancer and other cancers.

I'm passionate about improving cancer care in Aotearoa, because "we must do better, and we can do better."

May Seager

Kia Orana. My name is May Seager and I live in Maungaturoto in Northland, Te Tai Tokerau.

I was raised in Auckland by my Cook Islands grandparents and then my parents. I claim both Cook Islands and New Zealand European/Papa'a heritage. I have lived in many parts of New Zealand in the North and South Islands - firstly in Auckland City and subsequently, several rural towns.

We are continuing to raise our family in Maungaturoto, where we have lived for 23 years. My experience with cancer ranges from having seen friends and family die from the disease, to now having my own personal journey of living with a diagnosis of metastatic breast cancer since 2017.

Ngāroimata Reid

Kia Tūpato!

Ka tangi a Tūkaiaia kei te Moana

Ko Ngātiwai kei te Moana e hāere ana

Ka tangi a Tūkaiaia kei te Tuawhenua

Ko Ngātiwai kei te Tuawhenua e hāere ana

Ko au te uri o Te Rarawa, ko Ngāti Kahungunu, ko Rangitane Te Tau Ihu o te Waka a Maui hoki. Ko Ngāroimata Reid ahau.

I am honoured to be able to add my voice to Te Aho o Te Kahu as someone who has experienced cancer as both a caregiver and a survivor. My first experience was when my paternal grandmother passed away from cancer in the 1970's followed by my father in the late 1990's as a young man of 48. My sister was diagnosed in 2018, she is a survivor, followed by my own diagnosis in 2019.

I hope that my experience will enable others living with cancer and their whānau to be heard and improve outcomes for all.

Sarah Koopu

Ko Ōtukani te maunga
Ko Mōtu te awa
Ko Maraenui te Marae
Ko Te Whānau a Hikurukutai
Ngati Horomoana te Hapū
Ko Te Whānau a Apanui te Iwi
Ko Mataatua te waka

Ko Sarah Koopu ahau.

I spend my time baking, crafting, gardening, watching movies, dreaming, working in the Public Service in policy and operations, with a focus on Te Ao Māori, being a parent to two cats and a partner to Kevin. We live in Martinborough where we are learning to grow fruit trees, vegetables and the garden of our dreams. I'm a Neuroendocrine Cancer patient, have received treatment both in Aotearoa and abroad and now muddle along living with the ongoing effects of my tumour 'Numpty'. Mauri ora!

Theona Ireton

Kō Theona Ireton taku ingoa.
Te Ati Haunui a Paparangi, Tuhoe, Nga Wairiki and Ngati Rangi ōku Iwi.
Nō Heretaunga au, Nō Otautahi iāianā.

I am currently employed in a Kaitiaki Hauora role by the Canterbury District Health Board (CDHB) for 15 years, supporting Māori and their whānau who have cancer.

I sit as a Māori representative on a couple health leadership groups such as, Te Aho o Te Kahu (formerly Southern Cancer Unit Alliance) Te Wai Pounamu Māori Leadership Group and Palliative Workstream (SIAPO).

I am a survivor of Non-Hodgkin's Lymphoma.

Vivian Hahipene

Nga mihi nui o te ra ki a koe i raro i te manaakitanga o te Atua.

I am passionate about improving the health and relevant services for cancer patients, equity across the board and about making a huge impact on the distressing statistics regarding cancer patients, in particular, with the Maori communities and prostate cancer.

I look forward to working with the group.