Phil Kerslake MNZM. New Zealand & International Cancer Patient Support Overview

GENERAL VOLUNTEER ACTIVITIES

For almost 30 years Phil Kerslake has been involved in an extraordinarily broad range of volunteer service activities delivered directly to cancer patients and their families and to the organisations that support cancer patients throughout New Zealand, with some work in Australia and United States. The following details a selection of involvements through this time to illustrate Phil's Work.

- Mentoring and counselling hundreds of patients and their family members in NZ, and Australia, and USA online, at the request of the patients or families. In NZ these are frequently referred to Phil by one of the Cancer Support organisations. This has involved Phil providing non-medical advice on coping best with treatments, the hospital systems and the recovery process itself. It also involves Phil acting as a sign-post to the various professional organisations that are able to deliver beneficial services for the people concerned (1989 – present)
- Writing opinion and thought pieces and editorials for Cancer Society patient Newsletters (since 1990s)
- Speaking to public forums on various cancer support-related topics (1998 present: see separate schedule following)
- Writes a regular article for Leukaemia & Blood Cancer New Zealand's patient newsletters
 Lymphoma Today and Myeloma Today (2007 present)
- Organised and convened Hutt Valley DHB's first 'Shave for a Cure' event with proceeds to Leukaemia & Blood Cancer New Zealand (2010)
- Features in three patient information DVDs for Leukaemia & Blood Cancer New Zealand (2009 [2], 2013)
- A Member of the Executive of the Wellington Division of the Cancer Society of New Zealand (2010 2012)
- Appointed as New Zealand's first International Hero of Hope by the American Cancer Society. Along with this position Phil was appointed the National Ambassador for the Cancer Society's Relay For Life event (2011 – 2012)
- Appears as a cancer survivor interviewed in the Cancer Society-sponsored feature documentary film *Healing Journeys: He Oranga He Oranga* (2007)
- Appears in the American Cancer Society's International Relay For Life film (2012)
- Has a written account of his cancer journey included within the Cancer Society Wellington
 Division's patient information package (updated several times, most recently 2010)
- Has reviewed and provided editorial feedback as either a 'consumer' or 'expert' reviewer on some of the Cancer Society's patient information booklets (i.e. Emotions and Cancer, 2010,

- *Life After Cancer*, 2011 and *Getting on with Life After Treatment*, 2013 also wrote the Foreword for this booklet)
- Reviewed and provided editorial feedback on New Zealand's first Cancer Services Directory, for the Central Cancer Network. Then was speaker and official launcher of the Directory at Hutt Valley DHB (2010)
- Participated in a branding workshop for the Cancer Society of New Zealand (2010)
- Member of the volunteer patient advocacy organisation Cancer Voices NZ (2006 present)
- Wrote New Zealand's most successful ever cancer patient support book Life, Happiness ... & Cancer (NZ 2006 present); also published in Australia, Africa and Poland, with a global edition released through online stores worldwide in 2013
- Represented New Zealand at the international Re-Building Lives Awards for lymphoma survivors in Vienna, Austria. From hundreds of nominees worldwide, won one of the three global awards (2007)
- Member of Co-Researchers' Group with Dr Richard Egan, Research Fellow, Cancer Society Social and Behavioural Research Unit Te Hunga Rangahau Arai Mate Pukupuku, Department of Preventive and Social Medicine, University of Otago Medical School "Psycho-social-Spiritual Supportive Care Research" (2012 – 2014).
- Has actively participated in many committees reviewing and developing strategies for New Zealand cancer and palliative care services into the future. I.e.
 - Member of Capital and Coast DHB's Cancer Control and Palliative Care Project Control Group (2007)
 - Member of Canterbury DHB's Health Services Planning, Cancer Workshop. Also delivered the opening and closing addresses for the forum (2007)
 - Member of Cancer Voices NZ Multi-Partisan Workshop to assess consumer representatives' training and selection criteria (2007)
 - Member of the Central Cancer Network's National Lymphoma Working Group and Stakeholder Consultation Group (2012 - 2013)

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PRESENTATIONS (1998 – present)

Since 1998 Phil has presented pro bono to audiences at forums the length and breadth of New Zealand as well as in Australia and USA. Phil's presentations range from smaller, informal and conversational, to large formal addresses, often as the keynote. Phil has presented to over 20,000 people at more than 150 forums.

Phil speaks mostly to groups of people affected by cancer. He has developed a number of research-based presentations on topics such as 'coping with a cancer encounter,' 'building a healing team,' and 'coping with the life-after-cancer experience.' All Phil's presentations have been extremely well-received and highly rated time and again (examples of feedback received appear below).

Phil also presents to cancer support and medical professionals on the many challenges of the patient experience, helping them understand it better so as to provide an even more effective and empathic service to their patients. He has a unique ability to translate the patient experience for professionals and to reach patients in ways that encourage them to act proactively in their own interests.

Phil speaks predominantly in association with New Zealand's and Australia's most reputable patient support NGOs, as well as with Medical Institutions, DHBs, PHOs and Medical Education Organisations. Examples of his Forum Hosts have included:

- Leukaemia & Blood Cancer New Zealand (Numerous: Northland to Christchurch, 2006)
- Cancer Society of New Zealand (Numerous: Centres from Northland to Invercargill, 2005)
- Breast Cancer Network New Zealand (keynote at their inaugural patient conference, 2007)
- Louise Perkins Foundation ('Sweet Louise' for Women with secondary breast cancer, Auckland and Wellington, 2010)
- CanTeen (Wellington 2006 & Christchurch 2007)
- New Zealand Oncology/Haematology Nurses' Conferences (2007, 2008)
- Hospice New Zealand Genesis Oncology Trust Breakfast Lecture Series 2007
- University of Otago, Wellington School of Medicine & Health Science (2006 2012)
- Central Cancer Network, 2010
- o New Zealand Clinical Research Conference, 2009
- New Zealand Institute of Medical Radiation Technology, 2008
- New Zealand Oncology Social Workers' inaugural Conference, 1998
- New Zealand National Duty & Clinical Nurse Managers' Conference, 2009
- National Hospice Palliative Care Clinical Nurse Educators' Forum, 2009
- o New Zealand National Psycho Oncology Conference, 2005, 2010
- Oncology & Haematology Registrars' Professional Development Forum, 2010
- NZ Parliament: Breakfast briefing for interested MPs and Staff entitled 'Resilience: the X-Factor in Fighting cancer,' 2012
- NZ's 2nd Holistic Cancer Congress (2013)
- Hutt Valley DHB, 2011
- o Canterbury DHB, (2007, 2008)
- o Northland DHB, 2009
- o Bay of Plenty DHB, 2007
- Manaia PHO (CME Program, 2007)
- West Coast PHO (Men's health forums in Reefton & Hokitika, 2007)
- Tauranga Trust Breast Cancer Support, 2007
- Te Omanga Hospice, 2008
- o Cancer Council Victoria, 2008
- o Cancer Council New South Wales, 2008

- Leukaemia Foundation Australia (2008, 2012)
- o Bone Marrow Donor Institute Australia, 2008
- Myeloma Foundation Australia, 2008
- o American Cancer Society, Relay For Life International Summit, 2011

Illustrative Feedback

- "What an amazing talk... Your talk touched me deeply on Saturday. I am sure that was echoed x 200 by the audience." Pru Etcheverry, CEO, Leukaemia & Blood Cancer New Zealand, Bi-annual Patient Forum, September 2012
- "I can't thank you enough for your amazing contribution. Your presentation was wonderful, really inspiring and humbling." Amy Munro, Support Services Manager, Leukaemia & Blood Cancer New Zealand, 2012
- "Phil was fantastic I have been here for 9 years and I learned a lot last night and saw things from a totally different perspective certainly made me think... He is an inspiration. We have had very positive feedback this morning." Wendy Paterson, Centre Manager, Wanganui-Rangitikei-Waimarino Cancer Society Inc., October 2011
- "On behalf of the Cancer Society, Wellington Division, I would like to thank you for presenting at our (National) Professional Education Seminar. Your presentation was very well received. Feedback from attendees has been overwhelmingly positive." Raewyn Sutton, Manager Health Promotion, Cancer Society of NZ Wellington Division, August 2011
- "Your presentation was absolutely bang-on, and I know everyone in the room was very much inspired by you and your philosophies on life." Sue Brewster, CEO, Louise Perkins Foundation ('Sweet Louise' for Women with secondary breast cancer), June 2010
- "On behalf of Breast Cancer Network NZ I would like to warmly thank you for the excellent contribution you made as a keynote speaker and workshop presenter. We were truly blessed with speakers like yourself who are leaders in their respective fields and were able to tailor the presentations to the audience with great skill and humour." Dell Gee, Conference Organising Committee, 1st NZ National Breast Cancer Conference, Breast Cancer Network NZ, November 2007
- "Thank you for presenting to the second breakfast lecture in the Hospice NZ Genesis Oncology Trust 2007 series... We are pleased to let you know that the evaluations have been overwhelmingly positive and complimentary. You are an excellent presenter..." Mary Schumacher, Chief Executive, Hospice New Zealand, May 2007
- "Thank you so much for doing the presentation. I have had great responses." Koral
 Fitzgerald, Member Support Manager, CanTeen, Northern South Island Division, July 2007
- "Phil, thank you very much for your passion, energy and expertise that are so apparent in your presentations. You have taken consumer and nursing communication to another level for us ..." Liz Horn, Manager, Support Services, Canterbury-West Coast Cancer Society, after hosting Phil at the National Oncology & Haematology Nurses' Conference, March 2007

Phil Kerslake MNZM. Services to New Zealand & International Cancer Patient Support

PHIL'S PATIENT SUPPORT BOOK: Life, Happiness... & Cancer (March 2006 - present)

For decades Phil had seen a gap in the literature for patient support. Having kept abreast of the genre since his first diagnosis in 1979, he felt they mostly did not address the psychosocial (emotional) concerns of patients, which research had identified were as distressing and often more so than the medical challenges from the patient's perspective.

Also, in his observation most books in the genre were written by medical practitioners and researchers, or by former patients, with each lacking an element to both inform and inspire the new patient. Those written by the medical and research fraternities tended to be dry with third-person information that made them difficult for some patients to connect with or be inspired by. Those written by patients could be inspiring, but were invariably lacking the practical and reliable information that would inform the new patient on how to better cope with and navigate the cancer journey ahead.

Phil believed a book offering guidance and information from first-hand experience that incorporated research-proven, practical psychosocial interventions would enable cancer and its treatment processes to be demystified for new patients and their whanau. As an outcome he believed the reader would gain a sense of empowerment and be encouraged to become actively involved in their treatment and recovery processes.

Honing his long-held vision for his book and finalising his contents page while undergoing treatments for his 5th and 6th cancer diagnoses in 2003 – 2004, he wrote the book in 2005, and published it early in 2006, closely working with the Cancer Society of NZ Wellington Division, which acted as a professional sound-board for the fresh approach Phil was taking to his book. The Work that resulted has been extremely successful. *Life, Happiness ... & Cancer* is:

- A book that provides proven, credible information and inspiration for people wanting to cope better with a cancer battle or to help a friend, whanau or family member to do so
- Written to fill a clear gap in the literature internationally vis-à-vis being written by a
 patient/survivor (therefore including first hand testimony) but providing the sort of
 information and advice only previously provided by medical and research professionals
- Supported and strongly endorsed by the Cancer Society and carries its logo on the cover
- The book's Foreword was written by Associate Professor Chris Atkinson MD, Medical Director and former President of the Cancer Society of New Zealand and the current Chair of Psycho-Oncology New Zealand, as well as the Chair and Deputy Chair of many of the task forces and working parties that developed the current Cancer Control Strategy
- Added to a scant body of literature globally that addresses the emotional and psychological challenges of cancer from a survivor's perspective

- Has been New Zealand's most popular and read cancer support book each year since its release, presently with over 17,000 copies in circulation in NZ
- Through efforts by both the author and the Cancer Society of New Zealand, benefactors have been secured to provide free copies for patients wherever possible. Both Auckland City and Wellington Public Hospitals have offered free copies to every new patient or a family member for some years. It is believed to be unprecedented that a cancer patient support book has been made available to New Zealand patients in this way
- The book was also published in Australia, Sub-Saharan Africa and Poland between 2008 and 2010, with an international edition released worldwide through online stores such as Amazon in June 2013
- The book has been accepted as a resource on the American Cancer Society's Cancer Survivor's Network. Additionally, the US Coping with Cancer Magazine, the world's largest cancer consumer's publication with a readership of 500,000, excerpted from Life, Happiness... & Cancer for a feature article in its November/December 2006 issue, entitled 'Are you coping effectively?'
- The book was identified by the African Medical and Research Foundation (AMREF) based in Kenya, as a valuable resource for the African environment. It was stated by AMREF's publishing Associates that publishing *Life, Happiness... & Cancer* in Africa was for the purpose of providing much needed training and reference materials on cancer to trainee health care professionals, in an environment where only a small percentage of locations have life-saving treatments most relying on palliative care interventions simply to relieve the patients' suffering
- The book has been endorsed and embraced by New Zealand's leading cancer support NGO's and others involved with supporting New Zealand's cancer-affected public. Hundreds of written testimonials have lauded the value of the book in New Zealand and internationally. A small selection follows:
 - "This has proved such a valuable tool for all our cancer patients... We constantly have to increase our stocks in our lending library to meet demand and having read it, I'm not surprised!" Pru Etcheverry, Executive Director, Leukaemia & Blood Cancer New Zealand & Vice-Chair of the (international) Lymphoma Coalition
 - "A must-read for cancer patients, their families and health professionals." Associate
 Professor Chris Atkinson MD, Medical Director of the Cancer Society of NZ
 - "I heartily recommend this sensitive, practical and life-affirming guide to dealing with the complexities and uncertainties of cancer." Associate Professor Roger Booth PhD, Faculty of Medical & Health Sciences, University of Auckland

- "Life, Happiness ... & Cancer comes with our highest recommendation ... Research has shown that for a significant percentage of patients, the emotional challenges of a cancer encounter can be as trying as the physical and treatment effects. Since some degree of emotional distress is a natural consequence of cancer for all patients, this book is a valuable adjunct to the medical treatments you may receive."
 Dr Andrew Simpson, Clinical Director, Wellington Blood & Cancer Centre; Chair of the Medical Oncology Working Group of the Ministry of Health
- "The book is fantastic I've had people requesting it for weeks now from our library so am able to loan out our copies!" Julie Holt, Patient Information Nurse, Cancer Society of NZ, Wellington Division
- "I am sure there will be many people in the future who will be helped through their own battle by this book." Hon Pete Hodgson, NZ Minister of Health (2007)
- "Treading on delicate territory, he is never presumptuous; always positive ... Friends who have lived through cancer recommend this book. What higher praise could there be?" Breast Cancer Network NZ
- "This is a wonderful resource for patients, families and health care professionals, and we will certainly recommend it to people." NZ Breast Cancer Foundation
- "This is a book that I believe can make a real difference in the lives of cancer patients from all walks of life, and one that I would certainly recommend to patients to incorporate as part of their recovery process." *CancerForum*, The Cancer Council Australia's national publication, November 2007, Volume 31 No. 3, pp. 181 182
- "I highly recommend Phil Kerslake's book... his beautifully written way of providing helpful information will be of great benefit to others facing a cancer experience."
 Doreen Akkerman AM, Board Member, International Cancer Information Service Group
- "This is a book that I believe would be of benefit for all people who are touched by the diagnosis of cancer... it has an uplifting message of hope and offers options of what one can do to assist oneself through this time." Juliana Buys, General Manager, Community Services, The Cancer Council Queensland

Phil Kerslake MNZM. Services to New Zealand & International Cancer Patient Support

PHIL'S MEDIA REPRESENTATIONS (2005 – present)

Phil's strategy has been to take advantage of media to get the value of psychosocial support for cancer patients as widely understood as possible in New Zealand. He has also appeared in the media numerous times to champion the needs and interests of Cancer Support NGOs at their invitation. The following details his media work:

TV Interviews

- 15 September 2017 Newshub 6 pm News (TV3). 'The Kiwi who has beaten cancer eight times.' (As an Ambassador for Leukaemia & Blood Cancer New Zealand on World Lymphoma Awareness Day).
- 19 May 2016 **Seven Sharp** 7.00 pm 'He's really, really brave' Kiwi Dad fights cancer for the eighth time.
- 4 February 2014 (World Cancer Day, as an Ambassador for the Cancer Society of NZ) **TV3 Firstline** 7.45 a.m. 'Let's talk about the 'C' word. Debunking myths of cancer.
- 16 October 2012 TVNZ 1, *6 p.m. News* 'Crowe has plenty of support' (after Martin Crowe is diagnosed with lymphoma).
- 27 June 2007 Good Morning Show, TV1 at 9.15 a.m. re: Re-Building Lives Award win (10 minutes)
- 31 December 2006 Canterbury TV: Interview with Jo Giles for the *In-Depth Show* (30 minutes)
- 10 May 2006 Prime TV *Holmes Show* at 7.30 p.m. (first of 3 guests for 1 hour show. Rob Guest also interviewed). Repeated on Saturday 13 May 2006 at 11 a.m. and in Australia on Sky channel 54 Sunday 14 May 2006.
- 8 May 2006 TV1s *Breakfast* by Paul Henry at 7.50 a.m. (8 minutes)
- 26 August 2005 *Good Morning Show* (TV1) on behalf of the Cancer Society of NZ's interests on 15th anniversary of Daffodil Day (10 minutes).

Radio Interviews

- 15 September 2017 Radio Live Drive. Live interview 4.20 pm for World Lymphoma Awareness Day.
- 11 July 2011 Radio Kidnappers (Hawkes Bay): Pre-recorded interview for the Cancer Society on survivorship.
- 26 March 2008 Fresh FM Nelson: Pre-recorded interview, and recorded my 'Teamwork' presentation for later airing.
- 25 March 2008 Newstalk ZB Nelson: Pre-recorded interview coinciding with Nelson visit.
- 9-10 July 2007 Newstalk ZB Wellington (replayed news item) re: Healing Journeys documentary movie premier.

- 21 March 2007 Radio Plains FM Christchurch at 9.45 a.m.
- 6 December 2006 Radio Live with James Coleman at 3.20 pm.
- 4 December 2006 Radio Pacific with Alice Worsley and Martin Crump from 12 1 pm (interview and talkback).
- 4 December 2006 Viva FM with Simon Dallow at 11.30 am.
- 7 November 2006 Radio Dunedin with Neil Collins.
- 5 November 2006 Newstalk ZB Wellington with Garry Ward on the *Garry Ward's Great Weekender Show*.
- 1 November 2006 Radio NZ Afternoons with Jim Mora.
- 31 October 2006 Pre-record with Radio Clutha (for upcoming Balclutha presentation).
- 29 August 2006 Newstalk ZB Nelson with Ian Fergusson.
- 28 August 2006 (8.10 am) Fresh FM (Nelson) Fresh Air Breakfast with Matt Lawrey.
- 25 August 2006 (7.40 am) More FM Wellington 'Breakfast with Nick & Justin.'
- 24 August 2006 Newstalk ZB Christchurch for 9 12 Show.
- 29 April 2006 NewstalkZB Wellington with Garry Ward on the 'Garry Ward's Great Weekender Show'.
- 3 April 2006 Radio NZ Afternoons with Jim Mora.
- 13 March 2006 Present: Weekly life coaching segment on *Good Morning* TVNZ 1.
- 25 August 2005 Radio New Zealand's In Touch afternoon show on behalf of Cancer Society of NZ.

Articles

National & International Magazines

"40 years of cancer. Phil's a living miracle." Woman's Day, September 11, 2017, pp. 40 – 41.

"Brave Dad. I'm a survivor." New Idea, March, 2012.

"Cancer to can do – brave family man inspires scores." *The National Business Review*, April 23, 2010, p. 12.

"Know your nodes." *The Listener*, Vol 215, No 3567, September 20 – 26, 2008.

"I beat cancer six times." **New Idea**, September 15, 2007, pp. 46 – 47.

"Are you coping effectively?" *Coping with Cancer Magazine* (USA), November/December 2006, p. 35.

"Life, Happiness ... & Cancer." *Pink Magazine*, October 2006, pp. 74 – 76.

"Survival tactics." New Zealand Woman's Weekly, April 17, 2006, pp. 61 – 62.

"I've beaten cancer six times!" **New Zealand Women's Weekly**, February 20 2006, pp. 22 – 23.

National & Primary Regional Newspapers

"Kerslake's no longer behind the eight ball." The Dominion Post, Saturday August 12, 2017, P. A19.

"Cancer battler's beautiful support." The Dominion Post, 11 May 2017, p. A11.

"National Portrait: Phil Kerslake – Survivor." The Dominion Post Weekend, 11 June, 2016, p C3.

"Cancer survivor's toughest challenge." The Dominion Post, 10 May, 2016, P A3.

"Free book for cancer patients." The Dominion Post, 5 May 2008, p. 6.

"Never look back – the way one survivor beat cancer." Weekend Herald, September 15, 2007, p. A9.

"Monty Python's path to coping with cancer." The Christchurch Press, March 26, 2007, p. A6.

"Survivor tells how cancer can change a life for the better." *Otago Daily Times*, 11-12 November 2006, pp. 49 and 51.

"Lessons from a consummate survivor." The Dominion Post, February 20 2006, p. A10.

Secondary Regional Newspapers

"Lessons from beating cancer eight times." Upper Hutt Leader, August 16, 2017, p. 8.

"Cancer battler 'humbled'." Upper Hutt Leader, May 10, 2017, p. 1.

"Happy outlook helps healing." The Nelson Mail, 26 March 2008, p1.

"Six-time cancer survivor inspires at education day." Southland Express, May 10, 2007.

"Strong message of hope from cancer survivor and author." *The Timaru Herald*, February 12, 2007, p. 3.

"Cancer survivor's message of hope." Wairarapa Times-Age, December 6, 2006, p. 5.

"The 'Big C' is not a death sentence." Gisborne Herald, 11 August 2006.

"Attitude crucial in beating cancer." The Tribune, 6 August 2006, p. 4.

Community Newspapers

"Cancer survivor offering support." Timaru Courier, March 6, 2014, p. 7.

"Survivor's kind words recognised." Upper Hutt Leader, January 8, 2014, p. 3.

"Cancer survivor recognised for years of struggle." Northern Courier, October 12 – 25, 2011, p. 5.

"Communication key." Hutt News, October 11, 2011, p. 2.

"Cancer survivor's message of hope." City Life North, July 18, 2007, p. 15.

"Award honours efforts to turn survival into support." The Norwester, July 9, 2007, p. 3.

"Outstanding effort rewarded." Northern Courier, June 20, 2007, p. 7.

"Cancer author's message of hope." Gulf News (Auckland), December 7, 2006, p. 30.

"Surviving six bouts of cancer." Capital Times, 25-31 October 2006, p. 6.

"Book on cancer a valuable resource." The Norwester, 9 October 2006, p. 8.

"Toolkit for life." The Independent Herald, May 2, 2006, p. 1.

"Coping with attitude." Northern Courier, March 15 2006, p. 5.

Various Other Publications (excluding cancer support organisations' newsletters)

"Phil Kerslake: Laughing, not dancing." Breast Cancer Network NZ's *Upfront Magazine*, Issue 77, February/March 2008, pp. 7 – 8.

"Make a greater difference – advocate for psychosocial support!" *Cancernet* Newsletter, NZ Nurses Organisation, Cancer Nurses Section, October 2007, pp. 5 – 7.

"Life goes fast whether you've got cancer or not." *Career Edge Magazine*, Issue 16, August 2006 pp. 12 – 13.

"Facing up to the 'big C'." Employment Today, August 2004, Issue 95, pp. 19 – 21.