

## **Helen Wilkinson's speech - Launch of the Pete Young Cancer Research Fund**

*Deb has asked me to talk about Pete tonight—and honestly, as his Mum it's an honour. Pete loved being outdoors and, on the water, —finding a photo of him with a shirt on was impossible!*



*Pete was truly unique, lighting up a room with just his presence. Remembered for his cheeky smile, infectious laugh, kindness, energy and authenticity, he found joy in the happiness of those he loved. Fun-loving and adventurous, Pete was a natural leader, always ready to help others and living life to the fullest, always on his own terms. Living more in 26 years than most do in a lifetime —and I am incredibly grateful for that.*

*I have so many wonderful memories, and I've heard many stories from others, each one making me proud. The spirit with which he lived—even before his diagnosis—is truly special.*

*For me, Pete's determination, and strength—even when his world was torn apart—were truly inspirational. When I think of Pete, I think of love: pure and simple.*



Deborah Henderson OAM, Helen Wilkinson and Pete's partner, Amber

*Let me introduce Amber, Pete's partner and the love of his life. They met 18 months before he passed away, a few weeks later, in a difficult conversation Pete told her he had leukemia, he then gave her an out and told her to think about, things very carefully. She decided they had something incredibly special and wanted to be together. She was by*

*his side every step of the way—loving, supportive, and truly remarkable. Amber and Pete were determined not to let blood cancer take over their lives. They found joy in camping, going to the beach, and spending time out on the water—doing whatever it took to hold onto a sense of normalcy.*

*She's still a huge part of my life, and Pete certainly chose well. We still joke "We are a lot alike, but let's not tell Pete"*

*In a cruel twist, 18 months after Pete passed away, Amber's beautiful mum was also diagnosed with aggressive CLL. She passed away last December after a stem cell transplant and complication with CLL. To have this happen once is hard enough, but for it to happen twice is unimaginable. Life is just not fair.*

*In Pete's case, he was diagnosed with CLL at just 23. Unlike the typical case, which mainly affects old men and is indolent, Pete's leukemia was complex and aggressive. Before this, he'd always been healthy and active.*

*Pete didn't want to be known as "the guy with cancer." Initially he kept his diagnosis private, determined to live as normally as possible. Over the next three years, he continued doing things he loved: riding motorbikes, skateboarding, hiking, and working in civil construction. When his energy was low, he learned new skills like fishing and boating, finding joy in new pastimes.*



*As Pete's Mum and a project manager, he asked me to accompany him to medical appointments, helping deal with the huge amount of information coming at him. I researched treatments and also latest trials so we could converse and understand the doctors better in making decisions. Pete's job was to live healthily and concentrate on getting better. Armed with this knowledge, we faced each new challenge together.*

*This is how I found Deborah Henderson, she appeared on the Project TV show talking about her monthly trips to the UK for the amazing drug Venetoclax, which at the time was not available here, I reached out after stalking her on Facebook. She didn't hesitate*

*on educating me and helping me. We found a trial in Australia and Pete enjoyed 6 months of life returning to normal on Venetoclax.*

*Over the course of his illness, Pete underwent many different treatments, including various chemotherapy's, immunotherapies, a stem cell transplant, and CAR-T cell therapy. His fight took us to Boston for 3 months during the height of the pandemic, because, as Pete said, "this is just what we have to do." Through it all, he never let cancer define him or take more from his life than necessary.*

*Pete passed away at age 26, thankfully we had made it back to Australia. (just!) He fought so hard and was so brave. I am incredibly proud of him.*

*Since Pete passed, we've tried not to be sad. Instead, we remember him with a smile, a laugh, and a great story.*

*Pete's doctors and nurses had a lot of respect for him. Many sent me messages about his bravery and kindness during his cancer journey. I want to share part of a special letter I received from one of his doctors Dr B. from Dana Farber Cancer Centre shortly after Pete passed away, he began by saying that many people were asking after Pete.*

*"I have never had so many people from so many areas interested in, and thinking of, a patient in this way. I have thought for a long time about why this is so. I think it was a combination of many things. He was so young to have to be fighting such a battle, and I'm sure that stuck with people. But it is deeper than that, because I have taken care of young patients before. I think part of it is how bravely and serenely he faced all that we had to offer. Despite so many procedures, tests, blood draws, clinic visits, etc he never complained and he was always the kindest man. This attribute is what people remember long after they met him.*

*" I also want to remark that Peter left an imprint on me, and as my career as a physician continues to grow, he will always -- always -- be a part of the physician I become. At least for me, I have found that it is not the patients that I cure that have the most impact -- it is the patients that I am unable to cure. For there, honestly, is where the greatest potential for growth and benefit lies, those are the patients we are doing research for, and those are the patients for whom I wake up everyday with hope. Because I hope that the next time, I meet a young man with a loving mother and a kind soul that perhaps we will have better drugs and more effective therapies. I hope that perhaps I can do more for that man than we could do for Peter. And I will never forget the patients like Peter who came before and taught me that what we have right now is not enough, and we must hope for a brighter future."*

*His words capture everything I hope for this fund.*

*It seems crazy that before 2017, I had never even heard of CLL. Now, the reality of this disease has deeply touched my life—first by taking my son Pete, and then Amber's mum. I have also come to know many others like Deb Henderson who are battling this disease, and I am struck by how many of them are younger than the typical patient.*

*It has shown me just how devastating CLL can be, especially for those whose leukaemia behaves in unpredictable or aggressive ways. It can be a heartbreaking and relentless illness, and its impact, particularly profound.*

*Before I wrap up, I just want to say a few thanks from my heart.*

*First, on behalf of our family, I want to express our gratitude for honouring Pete with this blood cancer research fund naming. It means that his name will continue long after his life and that he will be remembered.*

*To all the doctors, nurses, and researchers—both here and overseas and the Australian Government at the time, —all these people did everything they possibly could for Pete. You've shown our family so much kindness and compassion since his diagnosis and throughout his treatments, we'll never forget it.*

*To WEHI, thank you for making this dream a reality.*

*To the donors, your generosity is the foundation of hope.*

*To the future recipients, I know you'll be doing the hard work with the support of the WEHI and this fund to help research treatments and cure blood cancers. We're cheering you on. My dream is that one day, being diagnosed with blood cancer will be no worse than taking a daily pill—or best case, that there will be a cure for all blood cancers.*

*To Deborah Henderson and Nick O'Donoghue, thank you for hosting tonight and for being the driving force behind creating the Pete Young Fund for cancer research. Deb, through everything, you've become one of my dearest friends, you've championed Pete throughout his illness and beyond, despite having your own blood cancer journey and have pointed me in the right direction many times. I'll always be on your cheer team, just as you've always been there for us. You are truly special, as everyone here already knows.*

*To Pete, thank you for being the most courageous, kindest, loving, inspiring person I have ever known, you are so loved and so missed.*

*For me, the Pete Young fund is a way to keep his legacy alive. It means Pete's name might make a difference, turning the sadness into something greater— Greater than Pete was or ever could achieve on his own.*

*Thank you, all of you, for being part of this journey. Your kindness and generosity are truly appreciated.*

*Helen Wilkinson*