



My World

Bettina Ryll is a patient advocate and founding member of the Independent Melanoma Community Advisory Board. A qualified doctor, with a PhD in molecular biology, she gained a deeper insight into the reality of cancer, and fighting cancer, when her husband Peter was diagnosed with advanced melanoma. She now uses that insight to help others.

■ Why I chose to be an advocate

I didn't feel I had a choice. Going through the experience of advanced melanoma with Peter made me realise where things go wrong for patients, but also what can be done to make things better. Not doing it now would simply feel wrong.

■ What are the rewards?

I've learnt so much, not just about melanoma, treatment options and their limitations, but also how details that seem insignificant in health make all the difference when you are ill, about trials and how to access them, the shortcomings of research with regard to patients' needs, how to function under huge psychological pressure, how to live despite having death as part of your life, how to deal with friends and family and their grief, how to tell your children that their father is dying... I wish I'd never had to learn this, but it is rewarding that I can now help others in a situation similar to ours.

■ What I find hardest

The slow rate of progress. Melanoma patients don't have much time. The combination of slow progress with patients dying quickly is very hard.

■ What I've learnt about myself

I am far more resilient and less willing to give up than I thought, and I can find something positive in any situation. Peter and I packed goodie bags for our children's birthday party in the radiotherapy waiting room. We celebrated his birthday, just two weeks before he died, with cake and champagne in hospital. It was probably pure defiance, but those were good moments.

■ I'll never forget...

Our group of melanoma patients – Taron, Quentin, Petr, Patricia and Peter – who all died horrendous deaths but supported each other and made all the difference to the time we had together.

■ A high point in my advocacy work

At the moment I'm content if I feel that we've come a baby step closer to better trials for melanoma patients!

■ I wish I were better at...

Time-management. There is always so much to do and so little time!

■ What I value most in advocates

The ability to turn adversity into strength, courage and compassion and use personal experience to help others.

■ The most significant innovation for patients in recent years

The recognition that patients are not simply consumers of a service, but possess knowledge that can improve the situation for society as a whole.

■ Advances I would most like to see

More efficient ways of developing, licensing and reimbursing drugs, to ensure that patients are not denied access to potentially life-saving therapies for the sake of extended risk evaluation (after all, the risk of untreated melanoma is death). They should also not be submitted to inferior treatments or placebos solely to fulfill trial design criteria coming from an era when the exponential increases in efficacy seen in melanoma today were unthinkable.

■ What I wish health professionals would learn in their training

I wish they were made aware that most of them are future patients and it is in their hands to influence how they themselves will get treated in the future! I would like medical students to get the chance to meet patients as persons, not only as medical cases, because I believe they would then be able to deliver better care. ■