

From vitiligo patient to consumer reviewer – how the Cochrane Skin Group has contributed to my ‘career’ in vitiligo

I have had vitiligo for nearly 55 years. If anyone had said to me when I was most troubled by it that having this disease would enrich my life, I would have laughed. Although I was not too bothered when it first appeared at the age of twelve, when I was in my teens I wanted more than anything to be rid of vitiligo which set me apart from everyone. Like most girls my age I just wanted to be the same as everyone else, to blend into the background and not be noticed. However, there is no doubt that if I did not have vitiligo my life would have been quite different. It is an integral part of who I am and none of the things I do now would have been possible if I did not have vitiligo. This is not to deny the anguish I felt for much of my adult life, as I watched it slowly and then rapidly take over my body. No longer able to hide behind cosmetic camouflage I had to face this disease head on and accept what at the time felt like a life sentence.

During my mid forties I was at my lowest ebb as the condition worsened. I thought this might be due to the impending menopause but was told by a GP there was no evidence to support this idea. What is more, he said, vitiligo might be a form of leprosy! I was devastated but, much to my relief, I soon discovered for myself by searching through the literature that this information, though commonly held in some countries at the time, was certainly not the case. As a result of this experience I developed a burning desire to find out all I could about this disease. It became a major part of my coping strategy.

In my job as Subject Librarian for the Biosciences in what was then the North East London Polytechnic and later became the University of East London, it was easy enough to search databases for studies on vitiligo. I was staggered to find so little had been done compared with the other three common skin disease, eczema, psoriasis and acne. Vitiligo was a mess of different theories about its cause and inconclusive studies on its treatment, few of which had been conducted in England. At first I thought that the observational studies and case studies were proof that the treatments were effective. But as a dermatologist once said to me, “One swallow doesn’t make a

summer” and I realised that such small numbers of patients could not possibly provide good evidence for treatments.

One day at work one of the psychology research students noticed my growing depression and suggested I watch a programme on the TV which was about a Sri Lankan woman, Sarojini Ariyanayagam, with vitiligo who wanted to set up a patient support group. She was severely affected and I thought how brave she was to expose her vitiligo before the camera. I attended a meeting at St Thomas’ Hospital where I met around 150 people with vitiligo – I had never met anyone else with this disease and had felt very isolated up till then. I became involved with what was then the London Vitiligo Group which grew to become a national charity, the Vitiligo Society. At first, because of my experience as an academic librarian, I joined the Medical Subcommittee. I found that I had a special talent for demystifying medical terminology mainly because if I understood it then I could explain it. I wrote many articles for our newsletter and contributed to the production of information for patients and health care workers. Our main task in those early years was to raise awareness of the disease among the general public as well as health professionals. I eventually became Vice-Chairman, then Acting Chairman. When I took early retirement I became Chairman for 4 years.

This was a period of intense learning and growth in self- confidence. I found that helping others helped me, that I rather liked being the one who knew a lot about vitiligo (I still do). To my amazement I developed enough courage to do exactly what Sarojini had done – go before the media and on TV to raise awareness of the disease. I realised that people would only really understand the implications of vitiligo if they saw what it looks like. And so I became the public face of vitiligo, a position which was to some extent a mixed blessing.

So what of Cochrane? Well, every year the Society has a stand at the BAD and on one occasion I attended a talk given there by Hywel about Cochrane to a meeting of nurses. I was intrigued by his talk which explained the work of the Collaboration, an organisation dedicated to finding evidence for healthcare through systematic reviews. I was also interested to discover that there was a place in the Collaboration for the ordinary person to contribute to this work.

And so the seed was sown. I am not a scientist, I am a language graduate who just happens to love biology and who worked in a Biosciences library. But here was an opportunity to increase my understanding of the world of research and possibly do something concrete about vitiligo research in particular.

The clincher came when I attended a Skin Care Campaign workshop and met the members of the Editorial team of the Skin Group. I joined the Skin Group on the spot and started by handsearching journals. There was a team of 3 from the Society, one of whom later became a co-author of the vitiligo review. We went to the library at ST Thomas' hospital about twice a month. However, I soon got bored with that and progressed to commenting on protocols and reviews and even did a Spanish translation of an acne study. There were opportunities for training and I attended as many workshops as I could. I also joined the Consumer Network, a wonderful forum for discussion and exchanging ideas.

But all the time I had a growing desire to do a systematic review. It seemed that all my previous experience would culminate in this one achievement. This was a way to get the message out there. Vitiligo matters. It needs more and better research. After many years of frustration, hard work and some unexpected health problems the review was finally published last year. My involvement with Cochrane and the consequent belief in evidence based medicine has given me the opportunity to travel to places I would never otherwise have seen, to contribute articles to the medical literature, to meet and work with some amazing people both within the organisation and outside it. I became a member of the NICE Partners Council, sat on the Patients' Panel at my local hospital, joined INVOLVE, the advisory group that promotes public involvement in NHS research, sat on the Steering Group of the James Lind Alliance and also of the UKDCTN, not to mention giving talks.

A whole vista has opened out to me in this specific corner of the world of research. What a wonderful retirement occupation the Cochrane Collaboration is!