

Testimony of Paula McKeown

As a member of the Environmental Health Association of Quebec (ASEQ-EHAQ), the Association has always been and remains close to my heart to this day. It is extremely valuable and important, both on a personal and collective level.

When I first discovered I had Environmental Sensitivities, which is a disability, I was confused, isolated and felt demolished and abandoned. It felt like I had been kicked out of my own life. There was nowhere to go: The medical system had nothing for me I was a freelance filmmaker unable to earn my living.

When I heard the words “you have friends here” from the people working at the Association, it was as if someone had just thrown me a lifeline in a very turbulent sea. I cannot stress strongly enough the extremes of anguish, rejection, stigma and devastation created by this condition in the lives of formerly active, autonomous individuals, nor can I stress enough the sheer amount of hard work we must put in just to survive, day in and day out.

Without understanding what is happening to them. People can flounder for years before learning what to do to help themselves. ASEQ-EHAQ was the beacon of hope for me. The Association listened, validated my experience, answered innumerable questions and saw me as a person rather than a source of problems. I don't think I would have made it without them. They helped me with very practical matters such as washing clothes safely, and locating eco products. I remember one time when I lived in a housing cooperative and had to negotiate an accommodation for my disability. The coop wanted to use Varathane (floor varnish) on the floors of the flat below mine in January, and I never would have survived that. I had nowhere to run to either, so I was really against the wall. I had already consulted the *Regie du logement*, and I knew I could probably get an injunction. ASEQ-EHAQ accompanied me to the Board meeting of the coop, where I pled my case. Their presence as a representative of an established organization and their pertinent interventions gave weight to my arguments and strengthened my confidence. It became much more difficult for them to perceive me as an insignificant victim, and together we were able to sway a group of initially hostile people. Needless to say, I won my case.

From the outset, I knew we needed a strong lobby group, because individually, none of us could really make a difference to the wall of indifference we all face. I knew our need for housing, medical recognition and treatment, social services and social justice could only be addressed collectively. I have long been involved in community organization, so I have a good grasp of the time and effort it takes to effect this kind of deep-seated social change. The changes in mentality and policy needed to redress the injustice and stigma suffered by those of us who have been chemically injured are both far-reaching and profound.

Therefore, since ASEQ-EHAQ is our representative political and socially, I can only stand behind this Association for as long as it takes, and do what I can to help. ASEQ-EHAQ is now 1700 people strong. It has developed working relationships with government, universities, and other community groups. It has become an increasingly strong voice as our representative towards government and the medical profession. It has done an incredible job of educating the public. I have always been, and remain, proud to be a member.