

Lights, Lipo, Action!

Essay by **MARTIN MAILLOUX**



I was diagnosed with HIV in 1994 with 140 T cells. After seven years of antiretroviral therapy, I started to develop lipodystrophy. My legs got thinner, my belly got bigger, and my bum became almost “undetected.” With sunken eyes and shrunken cheeks, I felt like I had AIDS written all over my face. I looked weak, exhausted and sick. My family worried because they thought I was trying to hide a new terrible disease. I worried about my new metabolic problems, like rising cholesterol levels, which increase the risk of heart attack.

I switched one of my drugs—d4T (Zerit), because it's well known that it's implicated in lipodystrophy—to something more lipid-friendly. I also made some changes to my diet and did a lot more Taoist Tai Chi. Shortly after the switch, my cholesterol returned to normal and my body fat slowly began to reappear. In 2003, with the help of generous friends and family, I got shots of New-Fill in my cheeks to restore my face. With more Tai Chi, my legs and bum also came back.

During this time, I became more aware of the lipodystrophy stigma experienced by a growing number of PHAs—as well as the lack of relevant information and support. I was exasperated by the slowness of the health network to recognize the serious effects of lipodystrophy on the health, physical integrity and quality of life of PHAs. I wanted desperately to do something about this, so I joined LIPO-ACTION!—a direct action group in Montreal that was created by lipo-laden PHAs and their sympathizers. I was on my way to becoming an HIV Lipo Warrior!

The medicine of LIPO-ACTION! is taking action. Since the beginning of our public action campaign, we have seriously disturbed those who claim that lipodystrophy isn't so bad. By breaking the silence together, we inform,



sensitize and mobilize the public about the impact of lipo on PHAs. With 70 active members in Quebec, we've organized many creative and theatrical demonstrations at HIV events, where our lipo characters wear masks and balloons as bellies and humps, hold up placards with smacking slogans and shake our big noisy pill boxes. Our troop of “HIV mutants” and archetypal characters represents different facets of the reality of lipodystrophy, including the HIV Lipo Warrior (fighting for a better quality of life), The Scream of Munch (loneliness and despair), and the three insensitive and denying doctors—Dr. Blindpills, Dr. Bouché (deaf) and Dr. Motus (mute). The use of symbols enables us to fire the imagination and touch people. After a skit you can see the rising of dignity again in the eyes of participants.

In just a few months—with demos, workshops, lobbying politicians and the media, and participating in press conferences and meetings of AIDS organizations—LIPO-ACTION! has managed to break the silence about the reality of lipodystrophy. Now we can hope for a better response to a problem that is recognized.



I strongly recommend the medicine of LIPO-ACTION! By coming to our monthly meetings or creating a group in your area, you can better face lipodystrophy and strive together for concrete solutions. You can reach us by e-mail at lipoactionquebec@yahoo.ca. +

