

# Interview with Luís Mendão on HIV activism

## Transcription

My name is Luís Mendão. I'm Portuguese. I'm 58; yes, 58. I was trained as biochemist, but I never did use this title. I then was a barman for many times, but also owner of a night club for 15 years, I think. But I was involved in policy from the non-governmental sector. Since '84, so long, long time ago, I was one of the founders of an NGO on drug policy reform called SOMA. That was my first contact with HIV/AIDS. I am a patient with HIV *and* AIDS. No was [*sic*] these new patients that have only HIV. I was also co-infected with Hepatitis C that I did cure, but the liver is still in very bad shape last year. Back then it was my first contact with HIV/AIDS because in '84 we started to see, in Portugal, the first signs of an epidemic among people injecting drugs of HIV. At the time, we did not know about Hepatitis C.

I was diagnosed with full-blown AIDS in the beginning of '96. It was strange because I knew everything about it, but I didn't consider myself at big risk. Also, nobody proposed me to do a test. I thought I was going to die, what was not excessive from my side, it was the rules at the time when you had full-blown AIDS, the treatment was not very efficient, so I make my accounts. Then because there was a treatment revolution, that's one of the reasons why I became so involved in treatment advocacy, treatment activism and treatment literacy, was I got this triple therapy and things went well. Not well from the point of view of side effects, but one of the side effects was keeping me alive, so it was good. You still looking at me can see the signs of the treatments we had back in the '90s: the lipodystrophy and many other quite

severe side effects or adverse events that we had.

We were facing a health crisis, first in the United States and some European countries, among gay men that were being diagnosed with a disease that had no treatment that killed very fast. We didn't have nothing. It was a mobilisation of a community and then others did come in. But in the beginning, it was mainly about gay men, to demand research. I remember some motto that strike me: "We need good research. We don't need hysteria." This was one of the mottos that convinced many of us to do their part. It was, on one side, money allocation; on the other side, to follow very closely anything that was being researched for treatment of HIV/AIDS. We knew that the medical doctors didn't know nothing because it was a new disease for them, and that if we didn't mobilise enough resources, it would be very difficult.

One of the differences, but probably we will come back to it again, in my opinion at least, was that the dialogue with the pharmaceutical industry was much more tense than it is nowadays, because with the first drug, AZT – it was a drug developed for cancer that was in the shelf – it was set at a very high price. Then we around '92, '93, had additional drugs on the same class, and we understood quickly that two drugs worked a little better than one drug because of the patterns and the easy way to resistance of the HIV virus. Then we had an additional cost. Finally, in '95, '96 with the critical, because it was disruptive, innovation when we passed for another class and used three drugs at the same time, we had even to redesign the clinical trial. Saquinavir would not be approved if it was not the movement of the treatment activists saying that they need to redesign and compare two drugs versus three drugs and not two drugs versus a new class. It did, this is my opinion, many people did save the triple combination and make it earlier than what it would have been.

There was probably more passion because people were dying and it was a question of saving lives. We were ready to experiment

everything that now probably we don't need, because the alternative was to die, or experiment something that could also kill you. The risks that were acceptable in the '90s were very different than the risks on safety that are acceptable nowadays. Nowadays, things became a little more institutional. Discussions became more polite in certain ways, but for many of us, there is still unmet medical needs, there is still need for research, not only on HIV treatment alone, but also with the comorbidities and co-infections that people with HIV experience; and that we seem to be 'condemned to eternal life', so we are getting older and older. We also need to live with that.

I really think that this was also led by the need. There was the need for us to do this kind of things if we wanted to survive. If we wanted to have a better quality of life, we could not rely on the traditional regulatory bodies, on the medical profession, on the researchers, on the pharmaceutical industry and on the politicians that were deciding about allocation of resources and where to go on public health, etc. I felt, and still feel a privilege to being a part of a so a critical moment regarding the way we organise our societies.