

A PLEX among epigenetic specialists

How did I end up attending the 2nd World Symposium of Epigenetics in Zurich, me a "simple" PLEX*?

It all started in 2018 with the SYNERGIES programme created by Meeting for Minds, where I am a research partner in Lausanne. In August 2019, one of the current scientific associates of MfM SYNERGIES, Prof. Isabelle Mansuy, organised the 2nd World Symposium 'Epigenetic Inheritance: Impact for Biology and Society' in Zurich. Having a keen interest in science and medicine, I took a look at the programme and the subjects compelled me to participate, although I must admit, the titles used in the conference appeared complex and somewhat simplistic to my eyes. The fact that English would be the conference's operating language was an added challenge. So I went back over my old courses in biology and genetics and read some specialised publications on this burgeoning subject of epigenetics, to give me some chance of understanding a minimum of the topics under discussion. I have to admit, I got caught up in the process. So I was filled with a mixture of glee and apprehension when I showed up at the 'Ecole Polytechnique Federal' on August 26th and 27th. Finding myself alongside 200 renowned scientists was a little intimidating, to say the least.

Monday morning at the opening of the event, I was warmly welcomed by Isabelle Mansuy who recognised me immediately. Equipped with my badge, I sat next to rows of eminent specialists in epigenetics who not only had an entire field of study in common but also the convoluted technical parlance that comes with it. As a PLEX, I immersed myself in the presentations by taking notes and photos of the posted slides and visuals in order to store the knowledge and help me remember it all. The various speakers presented their research on the mechanisms that leave traces in our genes which are then passed on to future generations. What causes these epigenetic changes and where do we find them? Pesticides, for example, are factors in our environment that can alter our genome. But metabolic dysfunctions caused by food imbalances or somatic diseases such as diabetes also change how our cells work. More surprisingly, stress, obesity and possibly autism are health problems that can be transmitted to our children. Fortunately, we know today that these modifications are reversible. Positive life experiences or a caring environment also influence the functioning of our cells.

Although currently scientists are in the laboratory with using rodents to demonstrate their hypotheses, their ultimate goal is to improve the quality of human life, for people like me and other PLEX. But currently, this knowledge is too often compartmentalised in the scientific community. Through this testimony and an article I have written for a French-speaking mental health magazine, I feel my role is to "free" this knowledge from the cloistered world of the expert in order to bring it to a broader audience. Meeting for Minds - SYNERGIES allows a dynamic exchange of insights and objectives between scientific knowledge and the experiential knowledge of those who have lived with psychiatric suffering. By exchanging our views around mental illness, we can endow the research environment with a singular insight into human experience and our strength as PLEX is that we come from diverse backgrounds with different educations and professions. Our interests, our life experiences and our varied sensibilities contribute to this shared inheritance.

Last August, I was the only PLEX attending this congress, but perhaps, at the next, we will be able to be more numerous and eventually take the opportunity to testify what it is like to experience a psychiatric illness. The experience of suffering, with the stigma that this implies for the people concerned, and the knowledge that results from it, would complement the knowledge of the researchers on several levels so that they too may develop insights into psychiatric illness as a whole. And how mental illness affects everyday lives, everywhere.

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*PLEX: People with Lived EXperience of mental illness