

## A Wonderful Afternoon of Exchange Between a Researcher and People Touched by MS at the AISM Pescara Centre



*The luminous AISM Pescara Centre located in the park Villa Sabucchi in Pescara, Italy. AISM is the Italian Association for Multiple Sclerosis which was founded in 1968 and the section of AISM Pescara was created in 1994.*

On Thursday 22nd April 2021, I had the opportunity to spend an afternoon with people touched directly and indirectly by multiple sclerosis (MS) at the **AISM Pescara Centre**. I must be honest with you; I was a bit concerned by the language barrier as I have been studying Italian for only a year. Even though I am fluent by now, I was worried not being able to choose the right words to explain my research and ask questions to understand better how it is to be *Living with MS*. However, the second I walked through the door of the centre, I felt a friendly atmosphere and it became natural to talk and exchange with everybody present that day. I did not prepare any question as I like spontaneity and I did not want it to be an interview. I introduced myself as a researcher who would like to get to know them better and they understood I was a musician. I laughed (maybe I am not that fluent in Italian after all). With the help of Irene, occupational therapist, everybody understood who I am, and the questions abounded. At some point they were asking about physiotherapy and I had to tell them that I am working on MS at the molecular level and not in physiotherapy. **They encouraged me to continue the research on MS** and said I am doing a great work.

I also had the opportunity to meet the president of the section, Vittorio Morganti, who encouraged me as well to keep up the good work saying research is important and having people like me at the Centre is a great exchange to connect both parts, researchers and patients.



*From left to right: Maurine (PMSMatTrain ESR), Cristina (psychologist), Fabrizio (friend), Laura aka Lairetta (MS, diagnosed in 1991), Serena (MS, diagnosed in 2016), Irene (occupational therapist), Susanna aka Susy (Serena's 6 year old daughter), Viorica (MS, diagnosed in 2003), Nando (his wife had MS for 15 years, she passed away but Nando still comes to the centre), Giorgia (MS, diagnosed in 2016) and Marisa (MS, diagnosed in 1991).*

The people present that day were of all ages. The youngest is Susanna aka Susy, Serena's daughter. She is the little sun of the Centre, always laughing. Serena was recently diagnosed with MS, in 2016. Then, there is Giorgia, she is my age, 25 years old, and she discovered 5 years ago she has multiple sclerosis because of problem with her eye. Another person who was diagnosed with MS after having a problem with her eyes is Laura aka Lairetta. She explained to me that from one day to the next she could not see well with both her eyes and after a few scans she found out she has MS. The oldest person is 87 years old and was still driving a year ago. His name is Nando. He does not have MS but he lost his wife 9 years ago because of it. Being with his wife while she had MS for 15 years, he explained me you need to reinvent yourself everyday as the disease evolves and it is a perpetual re-adaptation not only for people who have MS but also for their relatives.

They explained me the impact of Covid-19 on their life. Indeed, before the pandemic, they would go several days a week to the Centre and do different activities. During the pandemic they had to stay home and most of them were afraid to leave their place. Therefore, it has been a very difficult period for them, and we hope the situation gets better soon. The good news is that by now, they all got one or two doses of the vaccine, so the horizon is brightening.

What I enjoyed the most during this afternoon is hearing them talking about all the events and activities organized by the AISM Pescara Centre they participated to: carnival party, theatre event, Halloween dress-up party, painting, drawing, music therapy, one week retreat in Toscana, DIYs...

I have just told you about an afternoon of exchange between a researcher and people touched by MS and it does not stop here. I am now involved in AISM as volunteer, and I will contribute to their yearly activities, Covid-19 and time allowing. Talking about activities, let me introduce you to our next event happening at the end of this month: **GARDENSIA.**



*Two AISM volunteers holding beautiful hortensia.*

**NEXT EVENT: GARDENSIA**

**DATE: 28-30 May 2021**

At the end of this month, during GARDENSIA, all AISM volunteers gather on 5000 Italian squares to sell hortensia and gardenia.

Last year we could not gather due to the Covid-19 lockdown. Let us hope this year will be different!



*A blooming gardenia.*