Syimposium speech

Dear professors, doctors, researchers, dear guests and colleagues,

I am here today as a representative of patients suffering from chronic fatigue syndrome, but also as a voice for many who, because of this disease, often cannot be present here or in the places that once made up their daily lives.

Chronic fatigue syndrome is not just exhaustion. It is the loss of that part of oneself that was once most alive – the ability to get up, to think, to plan, to live in continuity.

It is a disease that does not choose age, education, or profession. It does not only take away strength – but often also understanding of the environment.

For many of us, the hardest part is not just physical weakness, but the fact that society does not see us, does not understand us, and often misinterprets us.

An illness that is not visible from the outside is often perceived as intentional. And it is precisely in this invisibility that its greatest burden lies.

That is why it is important that today, in this place, we are talking about it together – doctors, scientists and patients.

Because only if we act together can we change the way this disease is viewed and treated.

Patients with chronic fatigue syndrome often go a long way – from doctor to doctor, from diagnosis to doubt, from hope to disappointment.

Many of us have heard phrases like: "Just rest", "It's from stress", "It's all in your head".

And it is in your head – but not as an illusion, but as part of a complex neuroimmunological disorder that requires understanding, not denial.

That is why the education of doctors and healthcare professionals is crucial.

Not because we doubt their knowledge, but because we want to help them hear and recognize us better.

Because it is one thing to read about the disease, and another to live with it – every day, in a body that struggles, and in a society that often does not understand. There is a code for our disease, but no cure. We pay for everything ourselves, and instead of support — we get silence. We fight twice: with the disease and with a system that does not recognize us."

Today, in the post-pandemic era, when more and more people are facing post-COVID syndrome, it has become clearer how close and connected it is to chronic fatigue syndrome.

Unfortunately, many are only now, through the post-COVID experience, understanding what our patients have been trying to explain for years – that fatigue is not laziness, that weakness is not a lack of will, and that the disease does not disappear when others lose interest.

We should use this moment as a chance.

So that what is seen now is never forgotten.

To use the experiences and data from the post-COVID population to improve the diagnosis and treatment of ME/CFS.

And together, through a multidisciplinary approach, to connect medicine, research and the voice of patients.

As a patient association, we often say that we are not only fighting against the disease – but also against misunderstanding.

That is why we jokingly said that our association might be more accurately called:

"The Association of Patients from misunderstanding."

Because that sentence hits the point – we fight to be seen, understood and accepted.

But in every joke there is truth – and in this one, there is hope.

Because as soon as a problem can be discussed with a touch of humor, it means that there is strength.

The strength to survive, to persevere, and to preserve dignity and cheerfulness of spirit despite everything.

Our desire is not only for our voice to be heard, but for a dialogue to be opened through it.

That patients are not just objects of research, but active participants in the process of understanding and shaping solutions.

That the needs for social and legal support are recognized, because many sufferers lose their jobs, income and basic security.

That the system adapts to those who cannot fit into its rhythm, because they did not choose the illness that changed the rhythm of their lives.

We need accessible doctors, educated social workers, flexible forms of support and understanding – at school, at work, in the family.

Because this is not just a matter of health, but also of human rights, empathy and solidarity.

Finally, I want to say that I speak on behalf of all those who could not come – because the disease keeps them between four walls, in a silence that often lasts for months and years.

But also on behalf of all those who believe that things will change – thanks to you who research, treat, help and listen.

Our message is simple:

Do not look at us through what we cannot do, but through what we are despite everything.

People who want to live, to contribute, and to be part of a society that understands that health is not just the absence of illness, but also the presence of support.

Our diagnosis is there, but our right to treatment — not yet. And that is why we are not looking for pity, but understanding and knowledge. That one day, instead of silence, we hear the sentence: 'I know what's wrong with you, and I know how to help you.'

Thank you for hearing us.

And thank you for believing that together we can move forward – step by step, and word by word – to a society that sees and understands those who are not always visible.

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President of the Association of Patients with

Chronic fatigue syndrome and crisis of consciousness