

Dear organizers, esteemed experts, dear colleagues and guests,

Warm greetings from Karlovac. My name is Sanda Špac and I am the president.

It is a great honor and pleasure for me to speak today on behalf of the Croatian Association for People with Myalgic Encephalomyelitis, Dysautonomia, and Fibromyalgia.

I would like to thank the hosts for the invitation and for the opportunity to be part of this important gathering, and especially Professor Milovanović, who warmly invited us to this congress and who for years has made an exceptional contribution to the understanding and recognition of CFS, dysautonomia, and related disorders.

Myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), along with dysautonomia and fibromyalgia, are not just medical entities – they are illnesses that profoundly affect the lives of those suffering from them and their families. These are conditions that require not only medical knowledge, but also understanding, empathy, and systematic support.

Unfortunately, in our country, as in many others in the region, the situation is still far from satisfactory.

### **Problems in Croatia**

In Croatia, people with ME/CFS, dysautonomia, and fibromyalgia face a number of serious obstacles:

#### **There are no specialized clinics for ME/CFS.**

Patients have nowhere to receive comprehensive diagnostics and treatment. General practitioners are often unfamiliar with the diagnostic criteria, and specialists do not have structured protocols or clear guidelines. Patients are forced to visit various offices – from neurologists and immunologists to cardiologists and psychiatrists – often without coordinated care or understanding of the underlying cause of their symptoms.

#### **Delayed diagnosis and misinterpretation.**

Due to a lack of education and awareness within the medical community, diagnoses are made years after symptoms begin, and many patients remain unrecognized or incorrectly labeled.

#### **Lack of a multidisciplinary approach.**

ME/CFS, dysautonomia, and fibromyalgia require cooperation among multiple specialties – neurology, immunology, cardiology, endocrinology, physical medicine, and psychology. However, in practice, such cooperation is almost nonexistent.

#### **Lack of rehabilitation and social support programs.**

Patients often lose their ability to work, but have difficulty obtaining disability benefits or the right to reduced working hours because the illness is not sufficiently recognized within the legal framework.

#### **Stigma and misunderstanding.**

Worst of all, many still believe these disorders are “psychosomatic” or “imagined.” This further deepens the suffering and isolation of patients.

All of this leads to patients feeling invisible and left to fend for themselves. Today in Croatia, unfortunately, we do not have a single official reference center for ME/CFS diagnosis and treatment – an alarming fact for a disease recognized by the World Health Organization for decades.

This is precisely why every opportunity for international cooperation is invaluable to us.

I am proud to say that, in the past period, we organized a joint webinar in cooperation with Slovenian and Serbian associations, with the participation of distinguished doctors and experts.

We especially wish to thank:

Professor Milovanović, who invited us to this congress and who, with great expertise and humanity, helps connect the community of doctors and patients. I must also emphasize that for the first time, our own doctors

took part in the webinars we organized on the topic of CFS. I greet them and thank them for their understanding and support.

This cooperation between associations and physicians from three countries has shown how unity and knowledge can change perspectives – from a sense of isolation to the creation of a community of hope and understanding.

Our wish is for this to be only the beginning of broader regional cooperation.

Together, we can work on:

- establishing regional guidelines for diagnosis and treatment,
- encouraging research,
- and creating specialized centers and clinics in every country.

Because every person living with these illnesses deserves access to treatment, dignity, and understanding – regardless of the country they live in.

On behalf of the Croatian Association, I thank everyone who believes in the importance of knowledge, empathy, and cooperation.

Thank you to our partners from Serbia and Slovenia, to our doctors, and to all those who do not give up on the fight for a better future for patients.

I believe that together we can build a system in which no one with ME, dysautonomia, or fibromyalgia is ever left alone again.

Thank you for your attention and for the opportunity to create change together.

---