Dear guests, distinguished doctors, and representatives of Balkan societies,

My name is Barbara Gross, and I am the President of the Slovenian ME Patient Association Zebra. Today, I would like to share with you the experiences of our members and the challenges we face in understanding and diagnosing complex chronic illnesses.

1. The Situation in Slovenia

In Slovenia, three very different conditions—fibromyalgia, ME/CFS, and burnout—are often treated as if they were the same disease.
Everything is simply labeled *"fibromyalgia."*

The dominant belief is that these conditions cause chronic, widespread pain linked to burnout, and that the nervous system is overreacting to something modern medical devices cannot detect. From this, many doctors conclude—sometimes even *state outright*—that the pain is exaggerated, without a real physical cause. And therefore:
"You just need a healthy lifestyle and psychiatric care."

As a result, our ME/CFS boards rarely take the illness seriously. They do not recognize ME/CFS as a distinct disease, and they have no guidelines on how to treat patients.
ME/CFS is almost always equated with fibromyalgia.

2. What Our Members Experience

Many of our members developed ME/CFS after a clear trigger—an infection, major stress, trauma, or another event. But even before that trigger, their health wasn't optimal. They simply didn't notice.

Why?
Because they pushed themselves. They wanted to be useful members of society, so they ignored or hid their symptoms.

And these "small" symptoms were many:
• stomach problems
• migraines
• body pain
• allergies or intolerances
• palpitations
• dizziness
• asthma
• frequent infections
• slow recovery times

For them, this was normal life.

3. What Is PEM?

One of the key symptoms of ME/CFS is **PEM—Post-Exertional Malaise**, or **exhaustion after exertion**.

Think about this:
When a healthy person goes for a walk, the body produces energy. Mitochondria—the cell's "energy factories"—make this happen.

But in ME/CFS, the mitochondria do not produce enough energy.
So when the person moves, the body **uses up** its limited reserves and does not refill them.

This leads to **hypoperfusion** (reduced blood flow) and **hypoxia** (reduced oxygen supply to tissues).
Both have been scientifically demonstrated.

4. PEM Is Not Exclusive to ME/CFS

Did you know that many chronic diseases—if left untreated—also cause chronic fatigue and even PEM?

ME/CFS is **not** the only illness that causes hypoxia in the tissues.

There are several diseases where PEM is constant, and others where it appears only when the disease is active or untreated.

Among our members, many conditions were left undiagnosed for years. Only after long journeys from clinic to clinic were they finally discovered. These conditions are serious, underestimated, difficult to diagnose, and doctors often lack clear treatment guidelines.

Here are the most common ones among our members:

- **Ehlers–Danlos syndrome (EDS)** – a genetic connective tissue disorder.
  EDS *always* causes PEM. Many patients also have POTS and MCAS; these three conditions overlap frequently.
- **Marfan syndrome, Loeys–Dietz syndrome, osteogenesis imperfecta**
  (Yes, even genetic diseases can go unnoticed—often!)
- **Polymyositis and dermatomyositis**
- **Vasculitis**
- **Lupus**
- **Scleroderma**
- **Mixed connective tissue disease**
- **Sjögren's syndrome**
- **Antiphospholipid syndrome**
- **Endometriosis**
- **Polycystic ovary syndrome (PCOS)**
- **Ankylosing spondylitis**
- **Adrenal diseases** – Addison's, Cushing's, others
- **Thyroid diseases**
- **Severe allergies and mast cell activation**
- **Intolerances** – not allergies, but enzyme deficiencies causing inflammation and endothelial dysfunction
- **Metabolic diseases** – gastroparesis, chronic gut issues, leaky gut
- **Raynaud's phenomenon, vasospastic angina, microvascular angina**

All these illnesses can cause chronic fatigue and, when active, PEM.

And there are many more.
Behind each disease there is a real person, with a real story.

5. What We Discovered

When we encouraged members to continue searching for answers, we found extremely serious conditions such as **CADASIL**, which can cause aneurysms, and **Parkinson's disease**, where tremors or skin changes were misdiagnosed as ME or fibromyalgia—and even after proper diagnosis, some doctors still claimed the symptoms were "psychological."

The same happens to patients who develop organ damage—heart failure or pulmonary hypertension—and are still sent to psychiatry instead of receiving urgent medical treatment.

We have members who were eventually diagnosed with **myasthenia gravis** or **multiple sclerosis**. They had swallowing issues, muscle weakness, and eye symptoms for reasons completely unrelated to fibromyalgia or ME—but were still told their pain and fatigue were exaggerated and unjustified.

Even with clear diagnoses, the blame is often shifted to the patient's psyche.
This is terrifying.

Let me be clear: **psychiatric support is valuable.**
When the medical system gives up on you, a psychiatrist may be the only professional who listens.
But psychiatric care cannot replace medical diagnosis—and it must not be used *instead of* medical investigation.

6. Why We Must Look Deeper

We want patients to discover the underlying illness causing their PEM and hypoxia—because **these conditions can be treated.**

Medicine *can* help, but only if we look beyond the most common explanations.

If the condition were simple and easy to diagnose, these patients would already have answers. The fact that they don't means we must search for the less obvious, less frequent causes.

When severe, poorly understood diseases go untreated—diseases commonly mislabeled as fibromyalgia, or ME, or burnout—patients' immune systems become exhausted. They become vulnerable to reactivation of EBV, herpes viruses, Lyme, Bartonella, Coxsackie, and others.

Their bodies are fighting constant inflammation and injury without proper medical support. Meanwhile, they must *prove* they are ill, they are sent back to work, they are not believed.

Is it any wonder their immune system collapses?

And is “a healthy lifestyle and psychiatric treatment” really enough for diseases like CADASIL, autoimmune conditions, connective tissue disorders, or adrenal insufficiency?

7. The Big Questions

So what comes first?
Is it the immune system causing the disease?
Or the disease—especially when untreated—destroying the immune system?

We do not know.
Medicine does not know.

Perhaps many people lived with an undiagnosed rare disease since childhood. They coped with “small” symptoms for years without realizing something was wrong. Then came stress, trauma, or infection—a trigger—and suddenly PEM appeared, along with a severe form of ME. They were diagnosed with ME or fibromyalgia, and all further investigations stopped.

Or maybe it’s the opposite:
The trigger came first, caused severe ME and PEM, the immune system weakened, and an additional disease—one they were predisposed to—was able to break out.

Which option is correct?
We don’t know.
And medicine doesn’t know either.

Thank you.

Thank you for listening, and thank you for being open to understanding these complex and deeply human stories. Our goal is simple: to improve diagnosis, treatment, and—most importantly—*the lives* of the people behind these diseases.