



Bozhidar Ivkov



Giving a presentation



My time as President of the Bulgarian Union of Disabled People



**Bozhidar Ivkov, Bulgaria**

My name is Bozhidar. I am a 56-year-old sociologist living in Sofia. I am divorced with two children – a daughter and a son – and I have two wonderful grandchildren.

I work as associate professor in the Institute for the Study of Societies and Knowledge at the Bulgarian Academy of Sciences. My professional interests and fields of research include the sociology of disability, social policy and social work with disabled people.

In my spare time I work as a volunteer for the Bulgarian Organisation for Patients with Rheumatic Diseases (OPRZB) and the Bulgarian Ankylosing Spondylitis Patient Society. I try to help them with my expertise on various social aspects of rheumatic diseases: legal advice, aids, etc and also as editor of their newsletters. I am also the editor of a scientific and popular science magazine called *Bechterew's Searches*.

I found out about the Stene Prize competition from OPRZB's website and Facebook group. I decided to take part and share my own, perhaps rather unconventional, experience of coping with Bechterew's disease, which I have lived with since 1971.

# That's how I grow older

**When I read the competition topic I remembered the words of Montaigne, who described old age as a powerful disease that develops naturally and unnoticed. "My God," I said. "How can you talk of healthy ageing with Bechterew's disease, where the pain feeds on your flesh and doesn't stop trying to consume your spirit?"**

**"I had failed to see the deep psychological and social aspects of the topic"**

But when I first read the topic I hadn't quite realised that I was seeing it only within its biological context, where it loses all

meaning. The terms "healthy", "ageing" and "rheumatic disease" taken together, mutually exclude one another. They are separated and lose their meaning because of the supremacy and dominance of suffering and pain, which narrow your world only into them. They shrink your world to dependence, to the imposed role of patient, to total medicalisation, to... I had failed to see the deep psychological and social aspects of the topic, the dimensions of which were much more important and truly meaningful.

I first saw the light when I read a short story about the musician Itzhak Perlman. At one of his concerts, this genius, who suffers from polio, painfully made his way on to the stage, finally sat down, put down his crutches, unbuckled the harness supporting his weakened arms, picked up his violin and started to play. He took his audience into the realm of light. But after the first few bars, fate intervened and one string of his violin snapped. Nobody thought he could possibly play a symphony with a string missing. But Perlman did. He continued to play, changing the music, composing and adapting it to his "crippled" violin.

**"The audience realised that they had witnessed a miracle"**

And afterwards? The audience realised that they had witnessed a miracle. The musician's superhuman efforts had helped them overcome something inside themselves. Perlman smiled and said modestly: "You know, sometimes the point of music is to make music with what you have left."

Making music with what you have left... Being a person despite the disease, the pain and the suffering, and to find in yourself the strength to reach out to the people next to you and help them to win life's little victories.

**"... Being a person despite the disease, the pain and the suffering"**



Participation in round table during presentation of the FIT FOR WORK report of the Work Foundation in Bulgaria



Walk for the World AS Day and waving for World Arthritis Day



Together with MEP Ivaylo Kalfin (3rd from left) and EULAR representatives after the round table discussion on the challenges of people with RMDs in Bulgaria

This brought to mind another story I'd heard. At the Seattle Goodwill Games, there were nine athletes on the starting blocks for the 100 metres sprint. They were all young people with various physical and mental disabilities. The starting gun fired and they were off. However, about 30 metres in, one boy tripped, stumbled a few paces and fell. He started to cry. The other athletes heard his cries, looked at each other and stopped running. One girl with Down's syndrome joined the fallen boy, gave him a hug and said: "Do you feel better now?" After that, all nine of them crossed the finishing line, shoulder to shoulder together. The whole stadium broke out in applause.

I realised that, throughout my life of fighting the pain and the slow but relentless onset of functional deficiencies that Bechterew's disease brings with it, I had never been able to run or play an instrument. Words were the only thing I had. And all the time, whenever the pain tripped me and I would fall, or a string snapped in my soul, there was always a friendly hand extended out to me – my

unquenchable thirst for knowledge. The hand of knowledge. There was the word. Aristotle, Montaigne, Pascal, Nietzsche, Weber, Durkheim or Hadjiski. Balzac, Dostoyevsky, Dickens, Vazov and thousands of other enlightened minds were there beside me, offering me a hug or a new violin. And I kept on getting back up and carrying on – I carried on playing the small and chaotic symphony of my life.

## "I carried on playing the small and chaotic symphony of my life"

After years of opposing medicine's attempts to break me down into organs, systems and what have you, I paused and started trying to help those around me – the "others", those who were "different", to get up and carry on playing, to play first fiddle in their own lives. That I was lagging behind didn't matter.

All I have are words. Words, which Sartre once described as loaded pistols. I melted them down and create small, silly and unpolished images of hope, of resistance – little figurines of knowledge – and attempt to share these with my friends. That is how I age well with Bechterew's disease. The rest – medicine, pain, trying to deal with pain and suffering – seem to have been relegated to second place.

Ageing well with a rheumatic disease is a state of the mind, not of the body. There is nothing beautiful or dignified about age, disease and death. The beauty and dignity lie in the choices we make. And I cannot – and will not – allow the disease or time to win the fight and make me invisible.

## "The beauty and dignity lie in the choices we make"

### Editor's explanations:

**Bechterew's disease** is a name sometimes used for ankylosing spondylitis