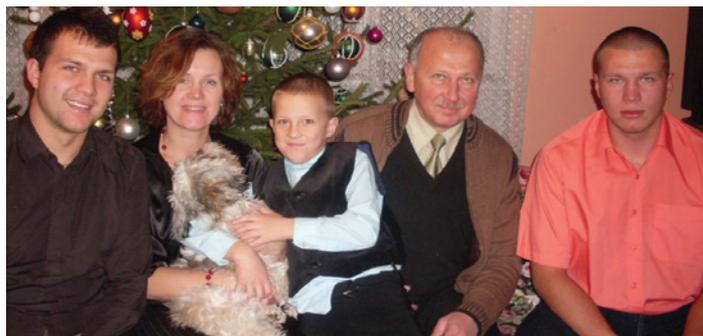




Violetta and her husband Czeslaw



My family



## Violetta Łodyga Poland

My name is Violetta and I am 44 and I have been sick since 1986.

I live in Zbąszyń, which is a little town located in western Poland. My diagnosis was made in 2001- SAPHO syndrome (synovitis, acne, pustulosis, hyperostosis, osteitis) and my treatment started then. I am married and have three sons. My hobby is crochet and embroidery.

As I was writing this essay I was thinking about those sick people who lose hope in their fight against pain. It's worth writing this to motivate people to fight against their illness and to show it's good to be alive so that dreams can one day come true.

# My 'friend' pain

## – Several years from the life of a person with rheumatism

**My name is Violetta and I am married with three sons. I have SAPHO syndrome and I would like to tell you about one of the most difficult, but at the same time happiest times in my fight against my disease.**

I live in a small town in western Poland. For 15 years doctors tried to diagnose my disorder. It was an extremely tough time in my life. I remember never-ending visits to doctors and the excruciating pain that lived inside me, which I was unable to tame. It was like a beast of prey that was always hungry. It made my life really difficult.

I remember a visit to my rheumatologist where I just stood and cried, unable to cope with the pain. Unfortunately, the doctor suggested I should be examined by a psychiatrist. The words I heard from the doctor, who was supposed to help me, hurt me a lot. However, I was ready to listen if it would only make the pain go away.

In 1999 I had my third son and that was the most difficult time for me. On the one hand, I told God that I did not want to live any longer, that I could not cope with the pain, but when I looked at my baby son, I wanted to fight. Elias was born prematurely. My doctor said, "If you can manage to breastfeed the baby until he is one year old, he will be healthy". I believed her. I was not strong enough to hold him in my arms or to change him many times a day. When I looked at Elias's smiling face I often cried because I couldn't lift him up or hug him. The pain pierced through my entire body, I could not breathe freely. My husband and my older sons were there for me, I saw their fearful eyes, wondering what the matter was with me. My family and friends were also very helpful. I could always count on them. Despite the pain, I fed him until he was thirteen months old. It was hard, if it had not been for the children, I would probably have given up. I often asked God: "Lord, how long will I last?" As an answer I heard: "I share the experience of the ones I love."

At that time I underwent numerous examinations. In order to diagnose me all contagious diseases, MS and other disorders had to be ruled out. There was still no diagnosis. My case was difficult to treat. I did not agree to a stay in a hospital – I could not leave my son. On the other hand, I did not want to live, as the pain was killing me.

**"I often asked God: "Lord, how long will I last?" As an answer I heard: "I share the experience of the ones I love."**



*My hobby - lace, embroidery*



*Carnival ball of the rheumatism*

One day I met a wise doctor who did not say much, but what she said helped me a lot, "Either you leave your children for a while, or forever." This is how I made the decision to go into the hospital. After a stay in the neurological ward I returned home without a diagnosis, and once again doctors recommended psychiatric treatment. I did not really care about the diagnosis; I just wanted the pain to disappear.

The gynaecologist who supported me in breastfeeding the baby convinced me that I was strong and perfectly sane. He claimed that no mother suffering from depression would have fought so strongly to breastfeed her baby despite the terrible pain.

I had another visit in 2001. This time it took a rheumatologist and a dermatologist only a short time to diagnose my illness as psoriatic arthritis. From then on, my life and appropriate treatment began. I had days with less pain and I finally knew what was wrong with me.

In 2005, doctors at the Institute of Rheumatology made a further diagnosis – SAPHO syndrome. It had been nearly 20 years since first symptoms appeared. My life, my will to act and my dreams came back. I had always dreamed of having a driver's license. I had already come to terms with the fact that the pain would not allow me to drive, that I would not be able to manage. Thanks to my treatment, I can now manage everything. I do not dream of driving a car anymore – I am a driver and I have passed the driving license exam.

**"I have never asked God why He has chosen me, but rather what the purpose of my burden is."**

I have thousands of never-ending ideas and dreams. I also have a hobby, crochet and embroidery, and I am able to enjoy it! In 2005 I co-founded a regional Branch by the Association of People with Rheumatism and Their Friends. I want to help others, so they do not have to wait for many years to receive the right treatment. When living in a small town, access to specialists, proper treatment and information are much more difficult to obtain than in large cities. Now, together with my friends and with the help of specialist doctors, we undertake awareness campaigns and help other people.

My son's diagnosis and treatment did not take as many years. He was diagnosed with Ankylosing Spondylitis at the Institute of Rheumatology. I know he is a brave boy. He has many beautiful dreams, just like I do. He is currently studying Tourism and Hotel Management at the Academy of Hotel Management and Catering Industry, he dreams about travelling and manages to fulfill these dreams. I hope that when he graduates, he will also have the energy to help others.

I have never asked God why He has chosen me, but rather what the purpose of my burden is. Now I know; I am stronger, I love life in spite of pain. Almost every morning starts like that. I have become friends with the pain. We know each other, sometimes we manage to be apart for a while, but my pain likes me and it soon returns. I accept this and do not try and fight it anymore. I know life is tougher with such a friend, but it is still possible to fulfill all my dreams.

I receive proper treatment, I have a rheumatologist at the Institute who understands me and does not send me to a psychiatrist. Although sometimes clouds appear, I always try to see the sun.