# Oana Maria Dan Testimonial[1]

My name is Oana Maria Dan, I am from Zalau - Romania and I am 30 years old. I finished High School ten years ago and did several training courses and now, I am working as a secretary for the Romanian Association for Rare Cancers and I am a volunteer in the NoRo Center – a Pilot Reference Center for Rare Diseases in Romania, where I also do therapy.

I am a patient with PraderWilli Syndrome-PWS, a complex genetic condition that affects many parts of the body, and psoriasis, an autoimmune disease characterized by red, itchy and scaly skin patches. I was diagnosed with PraderWilli Syndrome very late, when I was 18 years, but I always knew that I was not responsible for some of my health problems because I gained weight and could not stop eating if I had food available (as I always felt hungry).

When I was a child I had weak muscles and obesity, I could not walk and talk until I was 2.5 years, after enduring a rehabilitation program for 6 months. From childhood I had developed obesity and 3 years ago I was also diagnosed with psoriasis. Having obesity, my parents thought that it was just an irritation but, I was sure it was psoriasis from the beginning as I had read about it when a friend of mine, who is also diagnosed with epilepsy, had a severe form of psoriasis a few years before.

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It is a very unpleasant disease and sometimes it makes my life even more difficult than PWS. I cannot receive some therapies because of PWS and sometimes psoriasis has an impact on my behavior and attitude in society.

I am on growth hormone therapy but I started it very late as I was diagnosed late. It helped my muscle tone and my breathing. My treatment is free as we have a national program for rare diseases.

It is very difficult to be in front of the doctors or therapists with a problem and to understand that they do not know how to help you or do not understand you.

Once, I complained in the center that I could not exercise as my leg hurt badly but, my therapist thought that I was trying to fool her and was lazy. She only later realised that I had erysipelas, an acute infection typically with a skin rash, and I was right.

We can learn the symptoms, recognise them and support the doctors to help us faster but, they have to understand that we have to work as a team. We have to share our experience with other patients and learn how to support each other.