



This is me



Playing the guitar



My graduation



Maria Batziou Greece

My name is Maria and I am 36 years old.

I live in Athens, Greece, with my family. I like reading, dancing and painting in my free time.

I was diagnosed with Systemic Lupus Erythematosus in 1986. My motivation to participate in the Stene Prize competition first was the title "rare disease", which applied to my personal situation. Secondly, I needed to write down my feelings and my thoughts. I always believed that by expressing how you feel you get rid of negativity and tension.

My own friend

One day you wake up and your life is different. In what way? In many ways, in the way you live, the way you feel, the way you think and the way you behave with other people.

Your universe has changed. Especially when you are in your teens as I was, this change happened in a dramatic way. Who did that?

It's like an intruder in your life at the beginning, then a stranger and gradually he turns out to be an interesting visitor and maybe by the end he could be your friend. My own friend is called lupus and sometimes he reminds me of the well known fairy tale where the wolf devours Little Red Riding Hood, but most of the time he's a quiet dog.

In the beginning I had no idea what was happening. I'd never heard of this intruder. Only some scary rumours about what dangers he could bring to my life, or even that he might be contagious from people who obviously had known nothing themselves.

So if you don't want to be haunted by unexplained fears and pitiful glances, you try to get to know him better and think why not make him your friend. It is true that when something is not widely known about or even worse, completely unknown to you, you are afraid. However, if you decide to light up darkness, it is no longer dark anymore and things become less scary. The same happened to me. I started getting to know my friend better, sensing him, trying to understand all the messages he was sending me and eavesdropping on my own body. I studied him literally and metaphorically. I looked for every single piece of information wherever I could and even invaded "my strange friend's Facebook" to discover his club and find more "friends/colleagues" from there. Of course, in my research I couldn't exclude doctors. In fact, they were the beginning of my research. It was inevitable to start with them. What did they say about my friend?

The doctors say he is rare and then they look at you with frowns and skeptical faces but they don't tell you anymore, at least not in the beginning, because you can't understand. They think, who are you to talk about medicine? In those moments they become demeaning, mean-minded men trying to play God. The fact is they don't know much either; they are like you, they are still exploring the "stranger", and some of them have never met him before. You help them to know him and you end up being partners in the same quest.

"In the beginning I had no idea what was happening. I'd never heard of this intruder"



In Athens



At home



My friends

Eventually the rare becomes familiar, you reconcile with him and move up to the next level. You have to explain everything to others and communicate your knowledge and personal experience. This is the most difficult task for me. Who is willing to listen to you without feeling prejudice, pity and fear? How do you tell them that it could happen to anyone? How do you persuade them that you are still a normal person, the same as you were before? How do you tell them that the only thing you really need is understanding? In the end, how do you claim your place in the world? It is a long process and you need patience as an ally.

Ultimately, you succeeded in being understood by some of the people close to you and then, suddenly, another problem comes up. When they see you full of energy, optimism and participating in life, they start to underestimate your situation and your needs. Your positive attitude doesn't match the description of the cruelty of your "friend". After all, you don't die; you don't have AIDs or cancer. You don't seem to have "real problems". Society has more serious concerns to deal with. Besides, who is willing to search for a possible solution when there are other more pressing problems and there is not even time or money for them? At that moment you have to reconsider things and, starting from the beginning, put them into the right order.

"Who is willing to search for a possible solution when there are other more pressing problems and there is not even time or money for them?"

You are a normal person like everyone else in the world, with the same rights and the same needs, but you happen to face some health problems that others don't. You cannot overcome them because they interfere with the normality of your life, but on the other hand you have no obligation to expose them to people's curiosity. It's a personal thing that you don't need to describe to others in details. You just tell them what they need to know.

Of course you have to recognise your problems; to face them and set them in the right context and convey to other people that although it is a rare problem but no less severe or less painful and you are no less one of life's fighters. You are special and, like precious stones, need special care. You cannot be ignored because they have never heard of your condition. Apart from this, there is no excuse for overlooking a problem because it is not a common problem or not very well known. Besides, who can measure and qualify the pain or distress in life? No one, not even God.