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LETTER TO THE EDITOR

The flying butterfly: A patient's journey

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One morning in April 2003, the diagnosis came: systemic lupus erythematosus. What could this be? What shall I do? How bad could it be, to bear the name of such a fierce animal?

I asked my rheumatologist while he was palpating for enlarged nodes, and my thoughts were flooded with questions... A year earlier, I had had a seizure. I asked some internists, who had then reassured me that it was just fainting. Four years earlier, I had uncontrollable movements and transient absent-mindedness. I asked my internist, who also then reassured me that I needed more sleep. Luckily, in 2002, I consulted a neurologist who suggested tests for multiple sclerosis: lumbar puncture, encephalogram, and many blood tests. My fits became more frequent and made me feel like I was going to die, and gave my loved ones a hard time. And so, lupus formally entered my life and became a part of it.

There were many hospitalizations for IV infusions, big doses of cortisone and many medications that made my face and body change. Many don'ts entered my life: no exposure to direct sun, no sugar, no salt, no alcohol: not even my beloved chocolate!

Compliant patient, obedient soldier! Every instruction by my rheumatologist was a law for me: wearing my sunscreen, and avoiding anything that could deteriorate my condition. Having a target of finishing my studies as a philologist, I was spending time in company with Aristotle, Socrates, Plato, Papadiamantis and Kavafis. My diploma was a fact, and along a new start in life with the man I loved. At last! A happy break in all this surrounding fog. Moments of happiness which you can only appreciate when you realize that nothing is for granted in this life.

But, after a while, a new strike. Flares of lupus and myositis with high CPK that made my body ache. Great weakness made any movement difficult to impossible. Forty days in the hospital in summer 2005, and I forgot what the outside world looked like. At the same time, renal involvement made things more and more complicated. High fever was a regular companion of mine, and

a group of doctors who were thinking hard regarding the best medications for this flare, always refusing my continuous request to go home. My only solace was my pink pillow and my colorful bed sheets that were giving some color to the cold white hospital room. Tears for my uncertain future gave in to my smile of willingness to live. Strong friendships with fellow patients, small walks along the long corridors - just a few more steps every time - and sneaking into the refreshment room of the obstetric clinic for an occasional ice cream treat. A birthday party for my 25th spring, and friendly - actually, more like a family - relationship with doctors and nurses of the rheumatology clinic made my stay in the clinic more tolerable. The corridors became familiar, and I began to get accustomed to the hospital smell. It seemed as if the clinic became my second home. Indeed - so it had. Finally, the long-awaited ticket of leave from the hospital came, as did my return home with new instructions and medications. The back-and-forth to the outpatient clinic would continue as if I was going to a friend's house for coffee. Waiting patiently for my turn until my doctor sees me with such a look that made me smile and kept my eyes bright until now. How important is a doctor for a patient! A small God. You hang on their lips, waiting eagerly for their next word.

As time passed, my social environment supposedly became more worried, more curious, and always cruel, ready to stick a smear of illness, as if it is a curse; a burden you did not choose, and yet assigned to carry on your shoulders for life. And I, trying to balance a husband, family, friends, and potential future employers, kept the health problem a secret. The psychological pressure was unbelievable: even more painful than the physical burden itself.

With 2008 approaching, the year of detoxification, while I was trying to get pregnant, a positive result flew us right to the sky. Yes, life is beautiful, but soon a pregnancy loss would come to kill the happiness. Three more pregnancy losses, and the sky darkens. Obstetricians are unequivocal: the lupus is to blame. I wanted to hate

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it, but I couldn't: I got used to living with it; to loving it. Sadness builds up and I am trying to find solutions. In August 2011, I felt exhausted with the smallest effort. I couldn't climb the stairs of my own house, and shortness of breath along with a dry cough accompanied my smallest activity. I was listening to my doctor saying this is lung fibrosis, and from his look I realized this was a serious development. I was looking for information on the Internet and asking colleagues, "but this is an illness afflicting smokers, and I haven't smoked a single cigarette", I was thinking. Unfortunately, a lung CT scan confirmed this diagnosis. Shortness of breath was present all the time. My spirometry results were poor and I was in the worst mental state. I refused to accept it: I lost so much weight, and depression loomed up. My doctors suggested chemotherapy. I refused it and was looking for alternative treatments, for I so desperately wanted a baby. What followed was large doses of cortisone, mild medications to keep my hopes for a baby alive - disobeying my doctors for the first time, but having them alongside me and supporting me with every step. Besides, that was what I liked about them: freedom to choose, and joint decisions. In April 2013, my fifth pregnancy came along, but soon came pregnancy loss. My lung fibrosis worsened. My heart broke into a thousand pieces and I asked for professional help. Even from the very first session with my psychologist, I saw things from a different perspective and much brighter.

I began to realize that I needed stronger medication for my lungs. In October 2013, I started mycophenolate. However, I continued searching for a possible alternative, that my doctors might be wrong: I was asking various people describing my problem. Pseudoprophets put forward easy diagnoses, as well as pneumonologists who refused to undertake my management, since it was so complicated. My therapy was effective and spirometry results slowly became better.

For those who do not know it, the symbol for this such aggressive disease is the butterfly. I have always had an unexplained love for butterflies. I love their beauty, their freedom, their flight, even the fact that they are so fragile – it was as if something connected me with them, as if I was feeling somewhat like it. I wanted to open my wings and fly. I decided to get involved, to make any negative experience into a positive activity. To do something for me and to help others who suffer from rheumatic diseases, to really offer. I started by attending rheumatology seminars and congresses, although I didn't understand much at first. I was keeping notes, asking doctors. With my rheumatologist's encouragement, I approached the Hellenic Society of Anti-Rheumatic League. The aim of the Society is to inform patients and their families, and at the same time promote prevention, early diagnosis, appropriate treat-



ment and rehabilitation of individuals with rheumatic diseases, ensuring better quality of life. Soon, I became a member. I attended various fora and I started flirting with the idea of making a branch of the Society in our city. In March I attended the annual forum of Europe Lupus. Europe Lupus is an organization set up by patients with lupus and applies to people with Lupus. The Europe Lupus patient panel is a conference where patients' needs and problems dominate the scene. What I learnt was a different approach of Lupus by patients from all over Europe, and the latest developments around Lupus.

I returned home with new information in my luggage and new friends. What I want to point out to patients is that it is imperative to learn about their illness. After accepting such a situation, they learn to listen to their body. The information a patient provides to their doctor is their best guide.

In small societies, like ours in Greece, any illness is a taboo: this must change, starting from ourselves. After all, a disease is not a stain: it is a condition that could happen to everyone. More than anything else, what I would like to see is a smile on the lips and optimism in the heart. Life is a nice journey. Open your wings and fly! Enjoy it. I never stopped hoping...I will never stop waiting for... My dreams, refuge and guide!