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fighting rheumatic & musculoskeletal diseases together

Edgar Stene Prize Competition 2017

Third place: Eszter Rozán, Hungary

"I am a 47-year-old writer, journalist and bibliotherapist. I live in Szombathely, a medium-size city in the western part of Hungary. I am married and we have a 14-year-old daughter called Zsófia (Sophie).

I received information about the Edgar Stene Prize from the Hungarian League of Patients with Rheumatic Diseases. I wrote my essay to share my experiences with the disease and help other people living with rheumatoid arthritis."

The Uninvited Guest

He arrived on a sunny summer morning and announced that he will be living with me from now on. I didn't yet know him, but I wasn't happy about the idea. I was living peacefully with my husband and my family and I didn't need an intruder. However, he was relentless. He followed me everywhere and, while I tried to ignore him, he made me feel his presence more and more.

It was the summer of 2004 and the weather was really hot, so we travelled to Lake Balaton in August to find refuge from the heat in the cool waves. As soon as we got out of the car, he arrived so forcefully I could barely start walking. My feet were heavy and, although we were walking on asphalt, I felt as if I was walking on small pebbles. While I almost forgot him in the shade of the aspens, he reminded me of his presence again when I went swimming.

"Go away", I said. "I don't want you at all!"

He just shrugged and stayed. I thought the best strategy was to get on with my life and pretend that he didn't exist… Perhaps he will disappear. I think his persistence merits respect because he didn't leave me for a minute. Instead, he insisted that he became a part of my life and wanted to stay with me forever. Some relationships are constructive and change our lives for the better, filling us with energy in everyday life. This relationship was definitely not of this kind. From the very first moment, he was bent on destroying me physically and mentally. He attacked on several fronts: he made it difficult to move, he caused me pain wherever he could – at first only in small joints, gradually moving on to more and more body parts – and he

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also started to impair my mood. After a while, I realised that this was no laughing matter and I must seek help to get rid of him. Before taking decisive steps, I made a last attempt.

“Will you go away, at last?”

He just shook his head, knowing I had no power over him. Time was passing by and I did not want to delay any further. There was nothing else left to do, I had to visit my GP. He followed me even there, but, as soon I entered the doctor’s office, he hid – as if he were ashamed. He did not show himself while I was with the doctor. Luckily my GP cannot be fooled so easily. When the doctor examined me, he was cowardly, lurking behind me. But my doctor sent me for blood tests to prove that my new companion really existed. I started to realise the nature of my new housemate, and I learned nothing good about him. His very essence is to harm those he lives with, interfering with their immune system and confusing it.

I wished that my GP was wrong, hoping that perhaps I had some other, less harmful disease. I couldn’t wait for the test results, which showed unequivocally that it was him indeed. I still hear his evil laughter in my ears, as he revealed himself. My doctor told me to keep my spirits up and this was not the end of the world – nowadays we can fight him very well, and even if we cannot send him away completely, we can keep him inactive. I decided to take up the gloves and do everything to break his power – we would see who would win this fight.

When I visited the first specialist, he started his childish games again – he hid, pretending that everything was fine. I understood his strategy: if he wasn’t discovered, we wouldn’t fight him, and he could continue his destructive work beneath the surface. However, there was evidence of his presence, albeit not conclusive – just a factor indicating his presence, although its level was not really high yet. My first specialist doctor was, indeed, tricked by him. While the doctor admitted that my new “friend” visited me, he thought that this would be just a fleeting acquaintance, and he would go away when he got bored. Of course, we could help oust him with some innocuous drugs and ointments, however, he would surely go away – that’s what the specialist said, confidently.

“We cannot exclude the possibility,” the doctor said, “that this was just a single visit, and he will never come back to you.”

Hearing this, I found new hope and started to believe that our unpleasant relationship would soon come to an end. I returned to my everyday tasks, dutifully applied the ointments and drugs I was prescribed, and was expecting a final goodbye. However, he stayed with me stubbornly and just laughed at my treatment. He attacked me more fiercely. He caused more pain in new and unexpected places. He did not let me be, even at night, devising new methods of torture. He was most confident in the morning, when he paralysed me so that I could not get out of bed. I often needed up to 45 minutes to start moving my stiff limbs. I was running out of time and I knew I had to act, or he would beat me.

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My second rheumatologist took matters more seriously. He knew that my “friend” was not a well-meaning visitor who only came over for a few minutes, and we had to choose a more aggressive strategy. He ordered a new, conclusive blood test and we started looking for sources of inflammation. Again, I felt a faint hope that my invader was something else. My tonsils were determined to be sources of inflammation, so I waited impatiently for surgery. I hoped that after removing my tonsils he would leave me alone as well. After the surgery I felt relief, however in a few days it turned out that he was just lying in wait to ambush me again.

It was already December, close to Christmas. He decided to surprise me for the holidays, and attacked me so fiercely that I could barely stand up. As soon as the surgery wound healed, we changed strategy and looked for more drastic “weapons”. The weapons we used were disease-modifying drugs. My invader usually does not like them and is weakened by their use. This was true indeed – he laid low for a while and I was able to restart my usual activities. However, this victory proved short-lived and, a few months later, my companion came back with a vengeance. Now he attacked my whole body so fiercely that deformation started as well. My future looked bleak.

One day, my rheumatologist showed me a leaflet. He told me I had an opportunity to try biological therapy as part of a medical experiment. He also told me that we were still in time and, usually, even the most stubborn of visitors backed away from this. Although a few unusually persistent individuals held on to their hosts at all cost, in most cases this treatment worked. I did not hesitate for a moment as my guest had become unbearable by this time. I could not open my front door without help and brushing my teeth was torture. I could not wait to get through the preparation phase. Then I received my first injection. I had to learn how to inject myself and, while that wasn’t very difficult, I had some difficulty preparing the solution myself. I soon got the hang of it. I felt relief even after the first dose. One hour after the first injection the stiffness was gone. My visitor was wailing. Improvement was gradual and my partner did not want to bid me farewell, but he had no choice.

I am still using biological therapy – now I get injections on a regular prescription – and, apart from a few attempts, my torturer has lost all his power. Sometimes, when I have a bad day, he makes a feeble attempt to return, however he is a shadow of his former self. I believe that I received help just in time, before more serious damage was done. Rheumatoid arthritis went away, or at least has disappeared from sight and stays dormant. I sincerely hope he shall never return.

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