

EDGAR STENE PRIZE 2019 RUNNER-UP VICTORIA SARKISIANTS

Russia



I am 36 years old. I was born in sunny Uzbekistan, but have been living in Moscow for almost 20 years. I am a happy wife and mother of three to nine-year-old Nicole, four-year-old David and Eve who is two. I was diagnosed with rheumatoid arthritis (RA) in 2016 – the same year that Eve was born – and I was plunged into the world of inflamed joints.

I am a journalist, but I have spent 16 years of my life working in public relations (PR) promoting various brands and companies. Now I am engaged in bringing up my children, family development, working as a PR-specialist and writing texts for various marketing tasks.

I learned about the essay competition from groups on social networks dedicated to rheumatic diseases and bloggers: Rheumatoid Arthritis on Telegram and Instagram, Rheumofactor on Face Book. I hope my experience can inspire someone, lift their mood.

Life takes on new shapes after diagnosis, but it continues. I am glad I wrote an essay as it helped me to look at life from the outside once again, to see and celebrate all its bright moments.

RUNNER-UP ESSAY 2019

“I can!”

Rheumatism

From the moment an individual is born into this world, nothing is ever quite the same. That ceaseless change remains consistently uncertain, whether leaving kindergarten or going to university. It remains a constant following marriage and after the birth of a child. Key events that occur in our lives change those lives forever. However, living life in a way that is new or different certainly does not mean “bad” or “worse”. It simply means “in a different way”. We learn to live differently, that’s all. Sometimes this is more difficult, sometimes it is more enjoyable and sometimes it is more painful. The quicker we accept this change, the quicker we can adapt to the new conditions.

Things will no longer be the way they used to be

My life has changed more than once. I finished school in one country and went to university in another. After changing my place of residence, I found new friends. I acquired an interesting field of specialisation and started out in my career. I got married and had several children. I became personally acquainted with rheumatoid arthritis. Each of these events has changed my life and has taught me something new.

Today I am a daughter, a wife, a mum, a friend and a professional. I am happy. I am certainly not prepared to give all this up, especially not for the sake of rheumatoid arthritis. Many people are surprised, because even a healthy person does not always manage to combine so many roles. Add to this a disease that obliges you to rebuild your whole life completely and to subject it to certain rules. The key to success is seeing rheumatoid arthritis as the perfect employer. I did not find my ideal employer – instead he is just like Father Christmas, arriving as if by magic at a children’s matinée. But when the play ends, the actor takes off his costume and becomes an ordinary person with his passions, vices and demands. My own ideal employer is a creation all of my own.

Who is my ideal employer?

For me, this is a collective image. Its foundation is me. Only I can build my life and consider different scenarios for the development of future events because rheumatoid arthritis means an absolutely unpredictable life. Today you are active, you spend all day at business meetings and in the evening you give a child a ride on a sled. Tomorrow morning, your joints hurt so much that you cannot get out of bed. On such days you cannot cope without assistance and non-steroidal anti-inflammatory drugs (NSAIDs). No one can predict when the disease will get worse, not even your doctor, so you should always take this probability into account and have a backup solution.

RUNNER-UP ESSAY 2019

I work...

as a wife: I try to give my husband enough time, attention, care and love.

as a mum with three children: I take them to their kindergartens, to school, to educational activities and to performances. I play, educate, love, scold and love them again.

as a housewife: I create a comfortable home for my family. I keep the house clean and tidy. I cook lunches.

as a PR manager: In a leading distribution company, I work on projects every day, communicate with contractors, implement projects from the moment of their creation to the delivery of the final report.

as a freelancer: I write marketing texts that are commissioned by clients.

I am my own director

No existing employer could create such a comfortable environment for me where I could successfully combine all of the areas of my life – especially during the periods in which my underlying disease is more active. Only I can do this. As an experienced director, I masterfully write the script of my life and lead the “film crew”.

I can work from home and I don't need to climb up to the fifth floor company offices of a Stalin-period skyscraper without using the lift every day. By losing a small percentage of my monthly income, I protect my knee joints. During periods of onslaught from my disease, I can spend the whole day in my pyjamas and woollen socks and write letters to my colleagues and partners while lying in a soft bed.

I can work from home and control my environment during flu epidemics in town. I don't need a daily commute on public transport where I place myself at risk of catching viral or infectious diseases.

I can avoid having to be shy during periods of exacerbation and, instead, sit in the office wearing knitted mittens. I work from home and I can apply a warming ointment to my sore finger, wear a warm glove and work right there.

I can live without fearing a negative reaction to my taking methotrexate in the office. I work from home and can sleep all day to fully recover. I can resolve my accumulated work tasks on the next working day.

I can avoid being torn between work and home. While solving work issues, I also allocate time for household chores, putting things in order, loading the washing machine, taking care of the children and so on.

I can prioritise and plan my time. This allows me to take orders from external clients and earn some extra income.

I can fulfil urgent orders at night when my children are peacefully snoring in their cots and the house is quiet. Then I can allow myself to sleep for a little longer in the morning and not rush to the office for the beginning of the working day.

I learn to live with rheumatoid arthritis

There are very many things that allow me to avoid having to go with the flow, instead permitting me to direct my life myself. Every day my whole family learns to live with rheumatoid arthritis. We do without nannies and helpers. The children clear away their toys, put things in place and keep the place in order. This helps make my housework much easier. The children know that their mother's hands can hurt and it is hard for her to get down on her knees and collect their toys. They also know that mummy will be hurt if she accidentally steps on a building block. My husband helps with cooking dinners, buying groceries, opening screw caps etc.

I work without being tied to the office. This allows me to choose what to do and when, and where to go. I do not need to ask my employer for leave so that I can visit the doctor or lie down at home.

So my ideal employer is a well-assembled puzzle, one in which different parts are harmoniously assembled into a single picture of a full and happy life, despite the presence of my rheumatic disease.