

EDGAR STENE PRIZE 2019

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My ideal employer

Work without barriers for people with rheumatic and musculoskeletal diseases



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The European League Against Rheumatism (EULAR) is the organisation representing the patient, health professional and scientific rheumatology societies of all the European nations. EULAR endeavours to stimulate, promote, and support the research, prevention, treatment and rehabilitation of rheumatic and musculoskeletal diseases (RMDs). Within EULAR, the national organisations of people with RMDs across Europe work together and develop activities through the Standing Committee of PARE. For more information please visit www.eular.org

STENE PRIZE BOOKLET 2019

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Removing barriers

The impact of rheumatic and musculoskeletal diseases (RMDs) has been well established, but much still needs to be done to raise people's awareness. The economic burden of these diseases is very heavy: their cost is estimated at more than 200 billion Euros per year in Europe. Recent studies show they are the most expensive of all diseases for European healthcare systems¹.

EULAR continues its work to demonstrate the impact of RMDs on society, the economy and the person – including families and loved ones. Many of these diseases are long term and worsen over time. They are typically painful and limit people's ability to move easily. In severe cases, RMDs can result in significant disability, having a major impact on both quality of life and people's life expectancy.

EULAR aims to reduce the burden of RMDs on individuals and society, and to improve treatment, prevention and rehabilitation outcomes. It created its annual Edgar Stene Prize competition to provide people with RMDs with an outlet to talk about their condition, their life, their work, their emotions – raising awareness with the public as well as policy makers. As EULAR President, I value the competition greatly. Who better to highlight the very personal impact of RMDs than the people who live with the conditions day in, day out?

During my years as a rheumatologist, I have heard many stories similar to those featured in this booklet. They have helped me understand what living with RMDs means to different people and how it is possible to take control despite having a long-term condition. Rheumatic diseases can have a profound effect on work capacity – they are the single biggest cause of both sick leave and premature retirement. This is all the more significant because so many people diagnosed with RMDs are of working age – and because, now, we are all expected to work many years longer. Being able to work is not only relevant for society, it is very important for the individual: being an active member of society is crucial for our self-esteem.

1. https://www.eular.org/myUploadData/files/EULAR_Ten_facts_about_RMDs.pdf

For these reasons, EULAR chose to focus on keeping patients with RMDs in work as one of the goals of our 2018–2023 strategy, and we implement this through our Don't Delay, Connect Today campaign and in World Arthritis Day activities. It is also the theme for this year's Edgar Stene prize competition. "My ideal employer – Work without barriers for people with rheumatic and musculoskeletal diseases" has allowed people to highlight the issues and solutions which can help support people with RMDs to work more effectively and even stay in the job they want.

Many of the stories you will read reveal the role that each pillar of EULAR – the patients, the health professionals and the medical doctors – plays in keeping people with RMDs as independent as possible. Working together, there is much we can do to help reduce and remove the barriers people with RMDs face.

It is my pleasure to present you with our winner Ovidiu Constantinescu from Romania, and nine runner-up essays from across Europe. I would like to take this opportunity to thank all the contributors to this year's Stene Prize booklet and I urge everyone to encourage friends, colleagues and peers to read and share the booklet.

Prof. Johannes Bijlsma
President of EULAR



The Edgar Stene Prize

“A great promoter of co-operation between doctors, patients and community workers.”

About Edgar Stene

First awarded in June 1975 at the EULAR Congress in Helsinki, Finland, the Edgar Stene Prize was created by EULAR to honour the memory of Edgar W Stene. Stene was the founder and Secretary-General of the Norwegian Rheumatism Association and himself a person with ankylosing spondylitis (Morbus Bechterew).

Preparations to create the prize followed the establishment of a new EULAR Constitution at the organisation’s General Assembly in Paris, 26 May 1973, which brought the “National Community Agencies active in the struggle against rheumatic diseases” into EULAR. The creation of a Standing Committee for Community Agencies, today called the Standing Committee of People with Arthritis/Rheumatism in Europe (PARE), was put into practice at the same time as the Constitution.

Professor J J de Blécourt from The Netherlands, the first elected EULAR Vice President representing PARE, said about the occasion: “We may speak of an historic moment in the history of EULAR. The basic philosophy behind this development is the fight against rheumatism can only be effective, efficient and extended when not only the doctors (rheumatologists) but also the ‘rest of the community’ take part in the work of EULAR (the management of the fight against rheumatism). This is a modern way of organising health care, research, fundraising, patient care, education, public relations, etc.”

Edgar Stene was born in 1919 and was a police sergeant, a sailor and a mechanic. During World War II he served in the allied forces’ navy and it was then that the onset of his disease began. The symptoms of the disease worsened and his doctor recommended hospitalisation, but he remained in his job because of the importance of his position as a ship’s mechanic. After the war, Stene was involved in welfare work. He played an important role in Scandinavian and international organisations, and received recognition from the Norwegian King and the Swedish Federation Against Rheumatism, among others. Edgar Stene was “... a great promoter of cooperation between doctors, patients and community workers”¹.

He advocated the union of people with rheumatic and musculoskeletal diseases (RMDs) in a specific organisation to provide a platform for effectively addressing the issues that concerned them. He also emphasised the importance of people with RMDs having an active and positive attitude towards their condition and preparing themselves psychologically and physically to face their challenges.

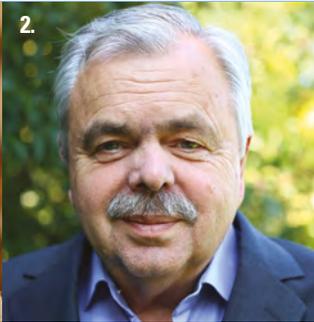
Rules of the 2019 Edgar Stene Prize competition

Every year, the Edgar Stene Prize is awarded to the person with a rheumatic or musculoskeletal disease (RMD) submitting the best essay describing his or her individual experience of living with their condition. Competition details are distributed to EULAR PARE member organisations so they can run the competition nationally. Member organisations select the best entry from their country to submit to the EULAR Secretariat for judging by the Edgar Stene Prize Jury.

For 2019, entry was open to people with an RMD aged 18 years and over. Entries can be submitted in the author’s native language as EULAR arranges to translate national winning entries into English.

The winner of the Edgar Stene Prize is announced by the EULAR Standing Committee of PARE on the EULAR website, via social media and in its newsletter. The value of the first prize is EUR 1,000 and the award is presented at the EULAR Annual European Congress of Rheumatology. EULAR covers the winner’s costs for attending the congress. In addition, EULAR will award the second-best essay with EUR 700 and the third ranking essay with EUR 300.

1. All quotes in the text are taken from the *Report on the Community Agencies presented to the EULAR Executive Committee* and the *Report from the liaison officer between community and professional agencies against rheumatism to the EULAR Executive Committee* (Zurich, 1973) by Professor J J de Blécourt (The Netherlands).



The Edgar Stene Prize Jury 2019 — Meet the Judges

Each year, a panel of people with experience or knowledge of rheumatic and musculoskeletal diseases (RMDs) has the honour of judging the Edgar Stene Prize competition. We welcome five judges who represent the three pillars of EULAR, and who come from different countries across Europe.

They are joined by the Chair of the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (PARE), the EULAR Vice President, representing PARE and the Jury leader who oversee the judging and offer guidance to the overall process.



1. Nele Caeyers, Chair of the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (PARE)

"I'm afraid you'll have to end your job as a teacher." This was one of the first things my rheumatologist told me after my diagnosis of severe lupus nephritis. I had only started the job five months before, right after my graduation. To fill the emptiness, I started working as a volunteer for our patient organisation, ReumaNet. I felt 'useful' again — the tasks gave me energy.

As a volunteer, I learned new skills and discovered talents I did not know I had. And people appreciated my work.

Twenty years later, I am using those 'new skills' in my daily job. I don't teach anymore, but I am busy doing other things I truly love. And that is what matters most: doing what you love and what you do best — whether as an employee, a volunteer or a care giver. We are not 'only patients', and all these inspiring Edgar Stene Prize stories prove that."

2. Dieter Wiek, EULAR Vice President, representing PARE

"After I got seriously ill at the age of 17 — I was diagnosed first with rheumatoid arthritis and later with ankylosing spondylitis — it was my goal to strive for the optimal education possible for me. My competences, interests and the areas where I could influence my daily schedule, at least a little, determined my career choice.

But if you have a lifelong chronic disease, with all the associated ups and downs, education, career choice, motivation and outstanding dedication are worthless unless there are various circumstances that enhance the ability to stay in work. Ensuring workplace adaptations, reorganising work, installing technical aids, flexible working times, home office if required are only some measures that support job retention.

Finally, it is important that you can disclose your health problems to your employer and your colleagues. If these health issues can be addressed openly and are treated in a supportive and confidential manner, it can have a significant impact on your health and ability to work.

I enjoyed reading the Edgar Stene Prize entries and experiencing what the ideal employer and a workplace without barriers is like for people with an RMD."

3. Polina Pchelnikova, PARE Board Member from the Russian Federation, is leader of this year's Edgar Stene Prize Jury

"I am both pleased and deeply honoured to have served as the leader of the 2019 Edgar Stene Prize Jury. The competition highlights various important RMD topics from the patients' perspective. This year's topic is particularly interesting and important because work is a crucial part of life for all people irrelevant of their health status. And, since RMDs are one of the main health problems in the workplace in Europe, this year's topic is very important for society in general.

It will be inspiring and useful for people with RMDs and other members of the rheumatology community to read these personal stories about finding the solutions for achieving proper working conditions and being actively involved in all the different spheres of living.

As a member of a patient organisation for people with RMDs, and as a patient myself, I realise how much will and effort is needed for a person with an RMD to stay active at work. Therefore, this topic highlights the importance of work and is also a way of showing other people that nothing is impossible. I hope this year's essays help people to think on their own experiences and inspire them to make their own achievements."

4. Prof. Annamaria Iagnocco, Italy, EULAR Treasurer

"The Edgar Stene Prize essays are inspirational for people with RMDs, health professionals and rheumatologists, and ensure the voices of people with RMDs are clearly heard by the whole rheumatology community.

Work is an essential part of life for all individuals and it is one of EULAR's main aims to improve the quality of life of people with RMDs and optimise their access to work. The topic of this year's competition, 'My ideal employer – Work without barriers for people with RMDs', is then of great value. It perfectly matches EULAR's objective to develop activities and related advocacy to increase participation in work by people with RMDs.

Being a rheumatologist highly devoted to optimising the management of people with RMDs, I was greatly interested to read such touching essays and I am deeply honoured to have served as a member of the Edgar Stene Prize Jury in 2019."

5. Erika Mosor, Austria, EULAR Health Professionals in Rheumatology Scientific Sub-committee Member

"I felt honoured to be invited to represent the EULAR Health Professionals in Rheumatology as a member of the Edgar Stene Prize Jury this year. All those real life stories and touching pictures are of enormous value to all of us – they give us an insight into life with an RMD and how obstacles in daily life can be overcome.

As work has a huge impact on health and well-being, I appreciated reading stories on this important topic about work without barriers for people with RMDs. Sharing personal experiences and solutions that have been found to overcome challenges in the work place will inspire and empower other people with RMDs across Europe. In addition, health professionals and researchers might be motivated to look for innovative solutions that enable people with RMDs to start working, stay employed or return to work again to a greater extent in the future."

6. Boryana Boteva, PARE Board Member and president of the Bulgarian organisation for people with RMDs

"Since I was diagnosed with ankylosing spondylitis in 2008, I have never stopped working. This is thanks to my employers who really supported me, trusted me and did their best to make me feel comfortable. I believe that staying active is essential for all people with rheumatic diseases nowadays. Working is not just a way of earning money – it helps us socialise and participate fully in everyday life.

The role of employers is really important for all people who have chronic conditions and that is why this year's topic, 'My ideal employer – Work without barriers for people with RMDs', is so very interesting. I was very happy to read such emotional essays and to find good examples of support and empathy."

7. Peter Boyd, Board Member of Arthritis Ireland and representative of Young PARE

"When I was diagnosed with rheumatoid arthritis and fibromyalgia in my mid-twenties, I was forced out of my job in hospitality. My employers were very accommodating, but the job itself was a barrier to my continued employment and I left in 2011.

Employment brought financial security, independence, self-worth and a myriad of psycho-social benefits that were lost through my diagnoses and new-found unemployment.

Work is not the only measure of the successful management of RMDs, but it has knock-on effects in many areas. Therefore, if an employer assists in breaking down the barriers for people with RMDs, then they deserve acknowledgement for supporting those who have so much talent, skill and experience to offer in the workplace. Returning to employment has given a massive boost to my self-management.

As a result, it's been a pleasure to be a member of the 2019 Edgar Stene Prize Jury and to read the personal stories of people with RMDs across Europe overcoming their barriers and being content in employment."

8. Tom-Erik Torbergsen, Board Member of the Norwegian League Against Rheumatism

"When I was 18 years old I was diagnosed with the rheumatic disease Morbus Still. In my case, it causes pericarditis and pleurisy, together with a lot of pain and fever, so my heart and lungs are regularly monitored.

For some years I was very sick, so I have felt the struggle to manage everyday life, and know how hard it can be to participate in sport, be social, get an education and so on. These days I am the chief pharmacist of a big pharmacy and I have a wonderful team which does an amazing job helping our customers with their medicines and health problems.

In 2017 I was lucky to become a board member of the Norwegian League Against Rheumatism, and I was pleased and humbled to be invited to be part of the 2019 Edgar Stene Prize Jury. This is an important and beautiful project, because the writers have invited us into their lives and their struggle. They help us readers to reflect on their – and maybe on our own – lives and experiences. They are an inspiration to us all."

2019
STENE PRIZE
WINNER



Ovidiu Constantinescu
2019 Edgar Stene Prize winner
from Romania



Talking about RA and patients' needs



Beating the drum during mass anti-corruption rallies in Bucharest 2017

An interview with a Straight Face

I was diagnosed with rheumatoid arthritis (RA) in 1996 and have subsequently had replacement operations on both hips. I've been a member of the Romanian League against Rheumatism (LRR) for more than 15 years, concentrating on helping with communication and advocacy matters.

In the 1990s I worked as a journalist with the BBC World Service (Romanian Section) in London. After returning to Romania, I worked as a public relations specialist with several companies in diverse fields such as oil and gas, legal, civil engineering and the media. For the past two and a half years, I have run my own small PR company, focusing on business communication.

I learned about the theme of this year's Edgar Stene Prize competition from the LRR but I was, of course, already aware of the competition from previous EULAR PARE activities that I had participated in.

So here I was... at the most important interview in my entire professional life. Let's face it, it's not easy to change jobs when you are in your mid-fifties. And Straight Face wasn't making things easier as he knew all the milestones of my career quite well: my successful projects and embarrassing failures, what I have achieved and what my weaknesses have been.

"Let's talk a bit about the work you may have to do here," said Straight Face.

"OK, but before we go any further I have to tell you that I have RA," I said.

"So what?" Straight Face's eyebrow rose up dangerously. "I have had RA for over two decades too, so don't you worry. You'll get your comfy chair, a proper desk, a computer, tea breaks, stretch-breaks and whatever breaks you may need, as well as a bit of

understanding about the days you will have to go to the hospital for medical checks," said Straight Face impassibly.

"My openness had achieved its objectives"

It seemed that my openness had achieved its objectives: a sort of a promise for flexi working hours, for a flexi-chair, for flexi-breaks. Even if Straight Face was irritating in his apparent lack of empathy, I felt that, somehow, he was with me.

"You know, I am a bit involved in the RA patients' league and I may need to do some work for them from time to time too," I topped up.

"Oh, that's quite OK. We like our people to get involved in the community, helping others less fortunate than them to cope with what life throws at them – RA included. You realise how fortunate you are, do you?" said Straight Face, as he upped his voice and fixed me with a deep radiology-like look that went straight through my bones and joints. "We see community involvement as a sign of enthusiasm and empathy, part of the company's values."

I had to admit that I had started to kind of like Straight Face. After all, he was not THAT bad.

“What about the salary?” I asked without any proper diplomatic introduction.

“100% performance-based. You perform, you are paid. You don’t perform and you get nothing. Based on what you have done so far, I am 100% confident that you will do OK. The wage is the last thing on my worries list,” replied Straight Face as he lowered his hand in boredom.

“Straight Face’s trust in my abilities was uplifting”

Well, it may be that MY wage is the very last thing on YOUR worries list, but it tops MINE! However, Straight Face’s trust in my abilities was uplifting and made me think that pushing hard may also be called job satisfaction or pride in a job well done.

“What about the working environment?” I asked.

“Now WHAT about the working environment? You know, you are quite a character,” blasted Straight Face at me. “To begin, you will be alone in the office – you will run the office, to be more precise. But we are looking forward to bringing in more dedicated people like yourself. You are fortunate to be in a position to build the working environment as it pleases you, so feel

free to bring in whatever makes you feel good and happy,” said Straight Face visibly annoyed.

“A-a-am I going to run the office?” I asked candidly.

“Oh yes, you will,” he said calmly but firmly. “You will take care of resources and deadlines; you will make coffee and tea; you will do presentations; you will listen to customers’ stories and write even better ones because this is what we do. We do ‘words for news’. Do you like our motto? I chose it,” said Straight Face proudly.

“I am afraid to r-run the office,” I whispered after a long and embarrassing pause.

That came down like the asteroid that wiped-out the dinosaurs, but, to my utter surprise, Straight Face didn’t laugh. Or, at least, I didn’t hear him laughing. He wasn’t dismissive either. He looked straight at me and smiled with some sort of encouragement.

“Be brave and face reality”

“Hey, what’s your problem? Cheer up,” said Straight Face. “You will be doing the same things that you have done for the past 20 years or so. You will write presentations and speeches. You will twist and spin the words. You will write wonderful stories out of bland business figures. Be brave and face reality: this is not a job, it is a chance. It’s take it or... or take it!”

Straight Face was saying everything that I was afraid to – and he wasn’t mincing his words. “There is no other way, pal. You have to run the office. You have to run the company. After all, it’s yours. You are way too young and unprepared to think about retirement or pension,” said Straight Face.

And then I fell asleep.

Epilogue

Two and a bit years have passed since I had that interview with Straight Face. The very next day I woke up and started working for my own business. As a matter of fact, I still talk to Straight Face now and then during my golden minutes when the brightest and creative ideas hit me – the 30 mins or so just before falling asleep.

Yes, I am running the office exactly as he said. I got myself the comfy chair, the comfy desk and I make the coffee every morning as I read the business papers. I take my stretching breaks and I do my bit with the RA patients’ league too, according to the company’s values and commitments. I meet a lot of people, listen to them work and write their business stories. I love what I do and I am proud of it. Now, I wouldn’t change it for the world.

“It is worth being happy without a reason rather than feel miserable without a proper reason. You are way too young and unprepared to think about retirement or pension,” said Straight Face to me again the other night.



Together with my colleagues

An interview with a Straight Face Ovidiu Constantinescu



Agora Conference in Bucharest – our national team

2019
STENE PRIZE
2nd place



Victoria Sarkisants
2019 Edgar Stene Prize 2nd place
from Russia



My big wonderful family



When everything hurts



I can work even when the children are at home

“I can!”

I am 36 years old. I was born in sunny Uzbekistan, but have lived in Moscow for almost 20 years. I am a happy wife and mother of three: 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 – when I was plunged into the world of inflamed joints.

I am a journalist, but I 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 Facebook. 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.

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.

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: I work on projects at a leading distribution company 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.



I can take my child in my arms again

“I can!”
Victoria Sarkisants



I can work without being tied to the office

2019
STENE PRIZE
3rd place

Your way

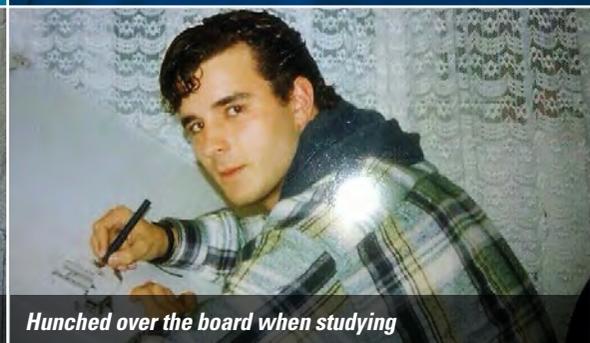


Francisco Carreira Roca
2019 Edgar Stene Prize 3rd place
from Spain

Working with incorrect posture in front of the computer



Access to the workplace



Hunched over the board when studying

Work right

I am an architect and, since osteoarthritis caused me a spinal cord injury in 2014, I have volunteered for NGOs such as Liga Reumatológica Galega and LIRE (Spanish Rheumatological League). I attend conferences all over Europe addressing several topics relating to the patient's role in society, in the work force, in shared decision making and in making new policies about us (that are currently being done for us but without us).

As an architect I also work as a volunteer consultant on accessibility issues, providing advice on how to improve our environment, in search of universal accessibility.

I was born in Lugo, Spain in October 1974 and have lived all my life in A Coruña. I have been happily married since 2014. We still don't have children but we have a wonderful cat. I like travelling and practising sports such as sailing or boxing. I also like reading and driving.

I first heard about the Edgar Stene Prize competition at the EULAR Congress some years ago and, as it is a prize given to some very inspiring stories, I hope you find mine inspiring too.

When I was at school I loved to draw. I spent hours drawing, hunched over my desk, my face glued to my sketchpad. I went on to study architecture, continuing to draw, hunched over the drawing board and, later, in front of my computer screen.

My mother always told me to “study law” and I responded that I liked to draw, that a law degree wasn't for me. However, she wasn't referring to the law, but instead to my posture. In Spanish, my native language, the word she used, “derecho”, is the same for the two different meanings.¹

“This marked a turning point in my life”

In my professional life, I continued to draw on paper before working on the sketches on my computer. The many hours I spent sitting with bad posture ended up costing me a great deal. I developed osteoarthritis. One fateful

day, I went to work like any other day, but the mere effort of opening the door was enough to cause a silent hernia (which I didn't know was there) to rupture, injuring my spinal cord. This marked a turning point in my life. In a matter of hours I went from leading a normal life – with a job, a partner, an athletic lifestyle – to being someone with a spinal injury, unable to move or feel anything below my chest.

A few emergency operations and years of physiotherapy have lessened the initial impact of the injury. This, added to my determination and the strength that my partner inspires in me, helps us support each other. Those who know us know that we are very positive people.

“I don't have a boss”

Now I work as a volunteer for various organisations. I don't have a boss, so I'm the one in charge of my postural health. However, if I were an employer – something I still haven't ruled out – I would think about certain things that I see but which aren't usually noticed. They are things that I would want for me and that I would put in place for everyone else.

If I were an employer...

As an architect, I was already aware of the importance of creating an accessible work environment but, as a wheelchair user, I have realised quite how many small details there are that can become insurmountable barriers. An accessible space for those with

reduced mobility is ALWAYS, and I put this in capitals for emphasis, a convenient space for everyone. Does anyone find the lift more inconvenient than the stairs?

“I would not hesitate to invest in the health of my workers”

If I had an employee who was in pain because of a repetitive task they were doing, who had to take time off and who could end up developing a rheumatic disorder due to premature wear and tear, as happened to me, I would carefully analyse whether this task was the cause of their sick leave. I would look for a way to adapt the task so that, when the employee returned, it would not do them any further harm. I would also introduce the same measure for all employees who do the same task since they would be exposed to the same risk.

As a result of my personal experience, I would not hesitate to invest in the health of my workers, whether they have a pre-existing medical condition or whether they become ill due to their work (and with greater reason in that case). Money spent on protecting health is never a waste, but an investment.

I would be very aware of the needs of my employees. I would be flexible about their work hours and I would let them work from home when, for health or work-life balance reasons, it's more

convenient for them than travelling to work. Breaks during the working day are also very important as they help employees concentrate and stop them getting tired or bored. A happy employee is a good employee.

I would seek to create a climate of co-operation, collaboration and understanding of the needs of everyone, striving to ensure that any adjustments and adaptations that a colleague may need are not perceived as privileges. Such modifications are aimed at ensuring everyone works in the same level of comfort based on their different capabilities.

A good colleague does not cease to be good just because they are diagnosed with a disease or because they need to change their working hours or place of work. This is something that all good employers should embrace and promote. A good work atmosphere is as important as a good salary – sometimes even more so.

“Work can always be done in better conditions”

Occupational health and safety measures, as I knew before my injury, are never a waste of money. They serve to prevent accidents and injuries, and to minimise the effects that these can have if they do happen. They are always a good investment, but few employers or employees see it that way. I discovered it in the most shattering way. Ensuring the correct

posture at work is a health and safety measure as important as any other.

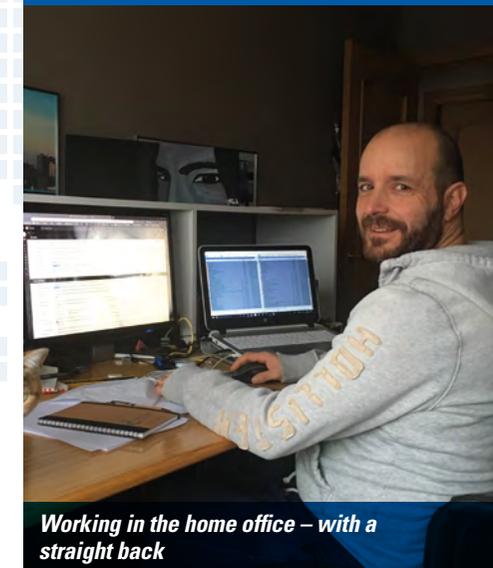
I don't know if I would be the perfect employer by implementing these measures, but there is one measure that would certainly make me closer to perfect: listening to the needs and suggestions of my employees and trying to facilitate their tasks. It is impossible to know everything, and the information provided by those who do the work day in and day out is very important. It doesn't matter if the work is something general like office work or something more specific, it can always be done in better conditions.

Working right is a right, an obligation and a good habit.



Working in a team

Work right
Francisco Carreira Roca



Working in the home office – with a straight back

¹ Editor's note: The word “derecho” used in the original Spanish text has various meanings: “law” (the discipline), “right” (as in “correct” and also as a “legal right”), and “straight” (as in “sit up straight”). This aspect is also used in the essay title.



Sibylle Van Remoorter
Belgium Flanders



Puerto de Mogan: A yoga session



Making Christmas decorations from twines and old fabric



One of my sand sculptures

My dream job. . .

I am 51 years old, single and was diagnosed with rheumatoid arthritis in 2004. I live in Berchem, Antwerp in Belgium. I trained as a sculptor and a nursery school teacher, but I retired last April due to my illness.

I first heard about ReumaNet, Belgium's patient group, and the Edgar Stene Prize competition last year during our family Christmas dinner. My sister was planning to submit a story and sent me the link. I don't know where she got the information from. I'm a good storyteller but not much of a writer, so this was a personal challenge. When I found about the topic, I felt motivated to write because my career has been pretty bumpy due to a lack of information, my head teacher and colleagues' failure to understand my condition and the frustration I felt.

I decided to participate at the very last minute because I believe it's important for patients to make their voices heard. It's not that easy to strike a balance between work and home life, taking

into account the limitations caused by rheumatism. Often doctors, family and colleagues forget about the impact that rheumatoid arthritis has on someone's life. The doctor who diagnosed me once said: "With the right medication you can keep your illness under control and lead 75% of a normal life. The problem is that you live 200%."

What do I think is my dream job? I think a dream job is the kind of job that doesn't feel like real work. And never fails to energise you in spite of all the hours you put in and the physical effort. You hop out of bed every morning, happy to go to work and all geared up for a full day of new challenges. You can put your talents to work and the great thing is that you even get paid for it.

After 10 years of working in education, the time had come for a new challenge. I wanted to put my training as a sculptor to use at last and I was offered an opportunity to work as a sand carver in Spain. A whole new world opened up to me, full of new challenges, foreign assignments, competitions and interesting meetings with like-minded people. In short, I had finally found my dream job!

“The results were a huge source of satisfaction”

I had no problem doing this very physical job 24/7, working non-stop to transform a mountain of sand into an impressive sand sculpture. The results, and the admiration of the visitors, were a huge source of satisfaction for me.

But I gradually began to suffer from inflamed joints in my hand. Initially, my Spanish doctor attributed it to the strain of working with the cold, moist sand. Unfortunately, I was subsequently diagnosed with rheumatoid arthritis and advised to stop creating sand sculptures immediately. The rheumatologist recommended that I return to Belgium and go back to my job as a nursery school teacher.

But I was determined not to give up my dream, which is why I turned to alternative medicine and diets. I tried to find solutions to reduce the heavy physical workload so that I could concentrate on the finer, more creative work which was also less physically demanding. My colleagues at the time were a huge support.

Unfortunately the flare-ups became increasingly frequent and severe. Some days the pain was so bad that I couldn't get out of bed and even needed help with simple daily tasks.

Under pressure from my family, and also for financial reasons, I decided to return to my job as a nursery

school teacher. I was welcomed with open arms and, in the beginning, people were very sympathetic and understanding. But this soon changed – perhaps because my colleagues had no idea how serious my illness and its symptoms were.

“Under pressure, I decided to return to my old job”

After a few difficult years, my head teacher, colleagues and I found a method that worked for us. We searched for solutions that everyone could live with. I was allowed to come in later every day and was given half a day off every week to recover. As a result, I was absent much less often. The school provided me with a “dictaphone” and a speech processor which reduced the burden of typing up observations, class preparation and reports. I am still very grateful for all the measures they took.

Recently I read ReumaNet's information about the various options available to help people with rheumatic disorders and I realised how badly informed we were at the time.

“The previous arrangements went out the window”

When a new head teacher was appointed out of the blue, however, all the previous arrangements went straight out of the window. The problems started again. Ultimately,

I had no choice but to go into early retirement – at the age of 49. You can imagine how deeply disappointed I was and why I felt as if I'd been relegated to the sidelines. I felt that, although my body was ready for recycling, I could still have put my talents as a teacher and my creative qualities to good use somewhere.

The first year of my retirement consisted of alternating flare-ups and bouts of pneumonia. That is when I realised that a full-time job was off the cards for me. I felt much better once I resigned myself to that fact.

“I focus on the things I can still do”

I no longer look back on the way things were or how things could have been. Instead I now focus on the things I can still do and I try to push back the boundaries. I find that my rheumatoid arthritis symptoms are far less severe in a warm and dry climate, and that a sunny setting gives me an overwhelming feeling of being on holiday.

As time goes by, I try to pursue my original dreams again as much as I can... travelling to exotic destinations, meeting interesting people and creating art.

I am fortunate that I was recently given the opportunity to stay regularly at a hostel on the Canary Islands free of charge in exchange for voluntary work.

The owner and the other volunteers understand my physical limitations and offer me fun, creative jobs that are not too much of a strain. This gives me a lot of satisfaction. The warm climate and my current anti-TNF therapy have gradually helped me forget that I have rheumatoid arthritis at all.



A free day with some other volunteers

**My dream job...
Sibylle Van Remoorter**



Vernissage September 2017: Together with friends for my 50th birthday



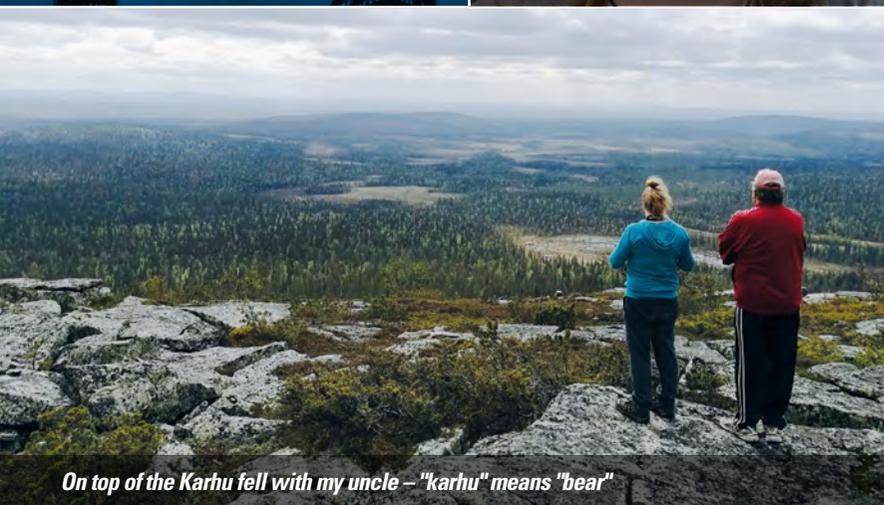
Susanna Lehtonen
Finland



My current passion is knitting
woollen socks



Travelling: Going to London by train in 2015



On top of the Karhu fell with my uncle — "karhu" means "bear"

My turn to shine

I'm a 47-year-old woman living in Oulu, Finland. I'm divorced and have three children – two sons and a daughter. I currently work as a school secretary in two elementary schools in Oulu and it is my dream job.

In 2006, I became ill with polymyositis which is an inflammatory disease which affects the muscles. Although the rituximab treatment I started in January last year has helped to some degree, I've found that cortisone is the most effective medicine for keeping my symptoms under control.

I do a lot of different crafts – they help me to cope with daily life. Reading and writing are also my hobbies. My disease has decreased my ability to do physical exercise, but I still walk a lot.

I learned about the Edgar Stene Prize competition from the Reuma magazine published by the Finnish Rheumatism Association. This year's theme seemed to be aimed directly at me. I felt that I had to tell my story because, sometimes, I still feel that it may not be true that I have my dream job.

When I was young, I was often asked what I would be when I grew up. I never knew what to say. I never knew what I would become. I didn't have a dream job. I was over 40 years old by the time I found my place in employment. By then, I had gone through studies for four different trades, various jobs, periods of unemployment, starting a family, illness and the breakdown of my family unit.

"I believed that"

They always say that no-one is going to call you out of the blue to offer you a job. I believed that as well. However, I had to re-evaluate this when I received a phone call saying that there was a job available and asking me whether I would come in for an interview.

I got the job and I liked it, but I wouldn't call it a dream job. It was a fixed-term contract and, once it ran out, I immediately received another phone call offering me another substitute position. I got that job as well, and that's how it all started.

"I found my dream job and my place in life"

A two-week contract turned into a permanent contract of four years and counting. There is no end in sight, for which I am glad. I had never even considered applying for a position in education, yet that's where I found my dream job and my place in life. I became a school secretary.

How did it happen? I still don't quite know. Sometimes I pinch myself just to check whether I'm dreaming. I suffer from polymyositis, a rare muscle disease. The doctors said my illness is an aggressively reactive type. Polymyositis – and the medication used to treat it – brought along co-morbidities and other health issues.

The disintegration of my family sent me into a spiral of hospital stays for various reasons. I was doing very poorly indeed. Sometimes I had little faith left and I wondered whether I would be fit to even live anymore.

“Everything went topsy-turvy”

Yet I did. I was quite certain I would not be able to work ever again. I was wrong about that, too. Everything went topsy-turvy but in the best possible way. The lyrics of a song play in my mind: “It’s your turn to shine”. And, yes, it is indeed my turn. I am worthy, able and needed.

At work I am not ill or disabled. At work I am a pro. Like a scout, I’m always prepared to help. I enjoy my work very much – and not just work, but also being able to do it. After all my misfortunes, it gives my self-esteem a boost.

Falling ill, and the difficulties following it, permanently changed my priorities. My job is tailor-made for me. It really incorporates everything I am interested in.

Perhaps my previous work experience – not to mention my life experiences – prepared me specifically for it. I have gained all sorts of knowledge and skills along the way. My experiences, and those of others, have made me grow as a person.

“I have gained knowledge and skills”

The hardships I’ve faced have forged me into an understanding and empathetic person. They are also the reason behind my positive outlook. When you are about to lose absolutely everything and then get another chance, it motivates you to give your best in everything you do.

I am surrounded by lovely co-workers whose example has helped me come out of my shell, little by little. Occupational well-being and ergonomics are priorities at work – not just for me but for everyone. We are all allowed to be human. Displaying emotions is allowed. Having a bad day is OK.

“I don’t see my work as a chore”

My co-workers and supervisors are understanding and supportive. Reciprocity is extremely important in a people-centred job like mine. I don’t see my work as a chore; rather I see it as helping and doing favours. When I do my bit as well as I can, it helps others do the same.



My current work – the dream job!

My turn to shine Susanna Lehtonen



The best thing in the summer



Erin McManus
Ireland



Having fun with my daughter, Leah, in a photo booth in summer 2018



Relaxing with my son Daniel on holiday in Orlando



Catching fish



With my parents in Disney World, Orlando

Retaining my self-worth

I'm originally from New York, but moved to Tokyo when I was 12. I was lucky to live in Denver, Singapore and Paris before settling in Dublin 22 years ago. I am 45 years old and was diagnosed with rheumatoid arthritis (RA) in 2014. I'm married to a wonderful supportive husband and we have two fantastic children: Daniel (11) and Leah (10).

At work I promote awareness of the challenges RA throws at me and the benefits of flexible working. I love travelling, spending time with my family, reading and going to the movies.

I heard about the Edgar Stene Prize from Arthritis Ireland. I wanted to enter because I have experienced the fear and uncertainty of working with RA. When I started my journey with RA, I found a lot of negative experiences and very few positive stories. I am lucky to have a supportive company and family, and would like to share my positive experience with others to confirm that, while hard, a lot is possible with RA.

I have worked in financial services for over 20 years. I've always felt valued at work – I love feeling part of something that is larger than myself and working to achieve a common goal. I have held a number of positions within large organisations and had been with my current employer for eight years when rheumatoid arthritis (RA) struck. I am a wife and mother of two, and I was at an exciting point of my career. A path for advancement was ahead of me, I just needed to push through the pain and get the job done. I had been feeling odd and somewhat unwell for over a year, but never thought it could be serious.

I refused to think that I required anything more than a short adjustment period post-diagnosis. I thought I was portraying normality both at work and at home. However, I'm not nearly as good an actor as I thought – everyone noticed and I hated that.

I could not concentrate at work – chronic pain and fatigue made it nearly impossible. Then the pain and crushing fatigue that RA caused meant that I found it difficult, if not impossible, to tolerate the commute to work and even harder to concentrate at work. I cannot take pain medication while working, due to side effects.

It was scary and thoughts raced through my mind at every waking moment (which there were a lot of as I had trouble sleeping). Where would my value in a professional environment be now? Would I be valued at home?

"I wanted to pretend everything was OK"

RA had built a barrier around me that chipped away at my sense of value. After a period off work to adjust to my

new “normal” and on the advice of my medical team, I met with my manager. This was very difficult for me to do as, for me, it meant acceptance of defeat. This was not something I wanted to do. I wanted to pretend everything was OK, but it was clear I was no longer able to work a full week. This was an imposition as a result of my RA. No amount of determination would give me the ability to work five days in a row or continue to travel into the office to work every day. I had to find a way to navigate around the barriers in my working environment and at home.

“RA changed how I perceived myself”

As the company I work for is a large multinational and has experience dealing with a range of dynamic abilities, cultures and beliefs of its employees, I expected tick boxes, forms and specific criteria. I was afraid – especially as I did not have a predictable condition and large organisations are not known for flexibility. I was afraid to acknowledge weakness and how that would impact their perception of my value to the organisation.

As a working mother I am acutely aware that I encounter unconscious bias against working parents. I was now faced with opening up regarding a weakness that I had no experience of managing. RA changed how I perceived myself in the organisation

and as a wife and mother. I knew the conversation I needed to have had to be formal, through official channels and not just a chat over a coffee.

The reception from human resources and management was not about demanding to know what exactly I could or could not do. They were interested in how much I had to offer and how, as an organisation, they could get value out of me without causing detriment to my health. The consensus was clear: I retained my value and the organisation would continue to invest in me. I could continue to serve, even with physical limitations. This was not the cold reception and negative response I had been expecting and I remain grateful. The company was, and continues to be, accommodating. Initially, I was afraid to accept the changes they proposed even though they are designed to diminish some of the barriers that RA imposes in the workplace, such as mobility, fatigue and pain. I thought they made me look weak.

“Equal does not mean the same”

Early on it became clear that the company was not trying to call me out as different. They wanted to mitigate the impact of the barriers caused by RA and allow me to continue to add value. I am able to work from home at least two days a week; in some cases when

I am having a flare, I can work from home all week. They have provided voice recognition software which really helps on days when the pain flares up. I have a medical rest day in the middle of the week to ensure I get the rest I need to be a consistent employee. I do not like needing these accommodations, but I appreciate the removal of many barriers to allow me to continue working. I have learned to accept that equal does not mean the same.

“I can continue to add value”

I am fortunate to work for an organisation that views people as having intrinsic value and the biggest asset to the services they offer. I have worked with a number of teams and managers since my diagnosis; some have been more understanding than others, but I have not come up against the overt bias that I feared. I have had to explain my circumstances to a number of people over the years. All have commented that they are sorry; there is pity as well as a lot of curiosity about RA and what it means to me. The focus, however, remains on how I can continue to add value. Retaining a sense of value in the work place is the most important support my employer could give.

My company strives to be, in their words, the “healthiest human system”. I am an example of how an open honest approach with managers

can make working with RA possible and rewarding. It is not all rosy: there is a lot of pressure and, at times I have to stop and rethink where I am putting my energy. I also have to make sure that I continue to communicate my progress by sharing more about my personal health and well-being than I would like to a broad audience. My hope is that my experience will help someone else along their journey. I know there are some who resent the accommodations I require in order to contribute to the organisation. At times it feels like these are the loudest voices and the fear of not contributing enough comes back to haunt me.

I am conscious of giving back to the organisation through representation on committees, such as our diversity and inclusion committee, participating in wider ability groups and speaking out about how I continue working with RA. I am still afraid of what will happen next. Will my treatment fail and will I be back to square one? Will I still be able to work to retirement age?

What I believe most of all is that without regular, sometimes uncomfortable, conversations addressing the unconscious bias towards illness and ability, I would not be able to feel valued. I am fortunate to be able to help on the journey to become the “healthiest human system” and retain my self-worth that working hard gives me, allowing me to cope better with whatever RA throws at me.



My family in Disney World – I’m with my mother, husband, daughter, sister and son

Retaining my self-worth
Erin McManus



With my Junior Achievement “More than Money” class



Lotte Wendrich
The Netherlands



Out of the Wajong (Dutch benefit scheme)



A happy weekend break



Drawing with chalk on the pavement



I love horses

No longer afraid to dream

I am 33 years old and live in Utrecht in the Netherlands. I am in a LAT (living apart together) relationship with no children. I am a trainer, consultant and illustrator. I enjoy playing games, cooking, drawing, walking and horse riding.

I sometimes think that my current job fell into my lap. And then I look back, giggle, and think: "Oh, no, it didn't." After all, I – and others with me – tend to forget the path that has led me to where I am. Things haven't always been that easy – and they still aren't. Which is why stories about this journey should be shared more often. Whether they are positive or negative.

We are not really sure whether I found my ideal employer or she found me. Or perhaps it was a series of fortunate events that prompted us to find each other: an idyllic situation.

To be honest, I couldn't believe that someone was actually offering me a job at the time. Why on earth would an employer offer me a job as a consultant? I mean, me? A person who had lost her youth disability benefits, who couldn't even get through a single day's work at the time and who didn't have a single qualification to her name.

It was obvious that my future employer saw something in me that I didn't see in myself. I didn't consider myself a good candidate on the job market.

I used to tell everyone that employers had to look at more than just academic degrees. That personality, character and experience were so much more important than a degree. What's that expression?... A case of the pot calling the kettle black? I am so happy that my employer saw me for who I really am,

that she could see the big picture. Finally, I ended up seeing it myself again and, more importantly, believing it.

"I finally dared to dream"

At the age of 17, I was declared unfit for the labour market. It was quite a downer for a 17 year old, but it also took an immense load off my mind. I finally dared to dream that, one day, I would be able to leave home and study. But things turned out quite differently. That's life, I guess. I moved into student housing, although I spent the first six months close to home.

I found studying to be a much bigger problem. It wasn't the match made in heaven I thought it would be. My body just couldn't cope and trying different types of higher education didn't change a thing: I just didn't get along with student life in that setting.

Volunteer work suited me much better however. From theatre to game fairs, children's film festivals and even organising holidays... I was the first one to volunteer and I gave it my all. I thrived and I did what I was good at: seeing people, helping them and enjoying the fun things in life together.

“My body and I disagreed”

New legislation and regulations forced me to gradually abandon my flexible and accessible volunteer work – I had to find a paid job because my secure youth disability benefits had changed. I was petrified. Although I knew there was so much more to me than that disabled label and a CV that offered more questions than answers, I had no idea how to convert that into an actual job. I understood that I would also need variation in a job and flexible working hours. But I hadn't a clue how to pitch this during an interview.

As a result, I only saw what my school reports showed: a smart girl who had never managed to get a degree or vocational qualification. The jobs the Dutch unemployment service recommended to me only compounded my fears: according to the law and regulations, I was now fit for intensive work in supermarkets. My body and I thoroughly disagreed.

I also realised I would soon become depressed working on the phone for an insurance company or in customer service. I know people are more than their jobs, but I did want one that would suit me a bit better – at every level.

I continued to do my volunteer work. And I chose the type of volunteer work that made me happy. Happy people were a prerequisite for me because happy people are pleasant. And sometimes they lead to something more, like a new job...

After a training weekend for one of my volunteer activities, I was approached by one of the trainers. She felt it was time to sit down and discuss how we could help each other. I wasn't quite sure what this could possibly mean but it seemed like a good plan.

So, one grey day in October, I stepped into a lift rather nervously. And, just under one hour later, I stepped out again completely overwhelmed. What had just happened?

“I had found what I was looking for”

When I got downstairs, I made a hysterical phone call to my brother. He had no idea what I was trying to tell him. That was fair enough because I talk nonsense when I flip out. And it was patently clear to my brother and his girlfriend that I was completely flipping out.

But, in between my idiotic shrieks, they made out that I had finally found what I was looking for. A job. A paid job. A challenging job. It was too much to think about right now. A job with opportunities to grow – as an employee, as an individual – in terms of work, knowledge and working hours. In which flexible work was the rule rather than the exception. Where the focus would be on me as an individual rather than just being a cog in the machine. And, above all, the kind of job where I would be treated like myself, Lotte, who is capable of a lot but who needs a break now and then.

Last year I threw a party because you should always celebrate when something good happens. It was a “Hurrah, I'm no longer on benefits” party because I wanted to celebrate the fact that I had earned enough in the past year not to need benefits any more. Something I could have never envisaged five years ago. Something I never imagined in my wildest dreams.

My job, and especially my employer and colleagues, have offered me much more than independence from benefits. They gave me the space to believe in myself again. They allowed me to become an individual who is gaining more ambition and guts every day, and who even has to stop herself from overshooting now and then. They have helped me realise where I was five years ago and where I am today. I am no longer afraid to dream and I dare to look beyond the norm and expectations.

“I prefer to prove it myself”

I no longer say that employers, or people in general, should look at more than just qualifications or social labels. I prefer to prove it to them myself.



Holidays!

No longer afraid to dream
Lotte Wendrich



I like to be creative



Marian's 7th birthday



Our family



Our son Marian during Christmas 2018



Our Christmas photo

Barbora Fartelová
Slovakia

When dreams come true

I am 36 years old and have been married to Marian for 10 years. We have a son, also Marian, who has brought light into our lives. We moved to a village a few years back – it is the village where my grandmother had lived – and I work in the kindergarten there that I established with my husband.

I have always loved movement and animals, but I was affected by rheumatic and musculoskeletal diseases (RMDs). I worked part-time with children when I was younger and it developed into my career.

Why did I decide to enter the Edgar Stene Prize competition? I want people with RMDs to know that we can live our lives to the fullest. RMDs come hand in hand with other illnesses, but we cannot give up. There is always somebody worth fighting and living for.

Rheumatism has taken a lot from me: a healthy mind, hope, dreams. It might sound unbelievable, but I am grateful for my ailment and that it has come into my life. I have given a large part of my life to it. It almost killed me, but I fought back and, today, I am stronger than any healthy person. I have even adjusted my occupation to my rheumatism. I don't think that a regular employer would tolerate my unexpected absences, inexplicable fatigue or mood swings.

My dream has come true. In spite of everything, we have a children's day centre. Yes, this work is demanding but it is fulfilling for me. There are days when I'm not able to get out of bed, when my blood pressure goes up, my head spins, I see double and my joints swell. I get dressed, I don't let on that my body hurts, I grit my teeth and I go to work with a smile. It's not far: our flat, the children's centre and my

husband's massage salon are all in one building. We employ a teacher who helps us a lot.

There are days when my joints twinge with pain, they are swollen and I can't leave my bed. When that happens, my husband sits next to me, strokes my hair and whispers: "Stay in bed, I'll open the school." Humour has an important role in our relationship, it keeps me going. That's why my significant other always adds ironically: "But don't lie in bed all day. It can't hurt that much." He knows very well how painful it is.

Well, I'd like to go further back in time... to my childhood. It all started one beautiful day when I fell off a bicycle and the wound on my knee just wouldn't heal. We visited several clinics and countless doctors. The outcome was clear: take a tissue sample from my knee. And that's when the cycle of misery started. The wound continued to discharge pus and, before it healed completely, I was in the surgeon's office again crying.

"It all had a purpose"

After they took a tissue sample, other diagnoses were made. I often wondered if it would have been better not to know about them. Today I'm convinced that it all had a purpose and

made me the strong person I am. My health varied as I grew up. Sometimes I managed all my activities – I went to the gym, I did aikido, gymnastics, I went jogging. But there were gloomy days as well, when my body just refused to co-operate and did not respond to my pleas and tears. When I went down with a virus, it was a disaster for my whole body. That’s when the doctors stepped in again and decided I needed to have my tonsils taken out. A simple procedure, right? Well, it was an indescribable feeling for a little girl to see the worn-out surgical chair with a belt to tie me to it. And it wouldn’t be me if things didn’t get complicated. They sent me home after the operation, but I woke up in the middle of the night with unbearable pain in my throat.

“Mummy, my throat hurts so much,” I cried. When my mum walked in and turned on the light, she saw there was blood coming out of my mouth and my nose. I don’t remember much from that evening, just being in the ambulance and my mum hugging me. I felt her heart beating fast, but she didn’t show me she was afraid. She kept saying that everything would be alright, that she wouldn’t leave me, that she was with me and that she loved me. Once again, I found myself in the scary hospital ward, in the scary chair. This time, they were trying to stop the bleeding, pushing tubes into my nose and my mouth. I just kept throwing up until the morning when the nurse removed all the tubes. The wound healed and life went on.

A few years later, I was accepted to a business academy and had my first romances. They were just innocent first loves, holding hands, first kisses. At that time, I was diagnosed with systemic lupus erythematosus (SLE), necrotising vasculitis and rheumatoid arthritis (RA). These diseases left large scars on my shins. The tissue tore as it necrotised and I had festering wounds there. When they healed, they left keloid scars behind, not to mention the swellings caused by rheumatism. You can’t imagine what that did to a young soul. I often cried on my mum’s knees – cried with pain, wanting to die, not wanting to live. Now I know that it hurt my mum much more than me.

“I couldn’t keep my diagnoses secret”

And then I grew up. One day, I met a great guy on the internet. After exchanging a few lines, we found out that we were neighbours, our parents knew one another and we used to visit one another when we were kids. And our first date? We couldn’t break away from one another. It took us hours to say goodbye. As soon as I came home, I got a message asking if I wanted to go out. Naturally, it was from Marian – that was my new love’s name. I couldn’t keep my diagnoses secret from him, he was a medical school graduate and he wouldn’t believe me if I told him that I just had “the flu”. One day, I showed him my scarred legs and asked: “Do you still love me? Even when I’m scarred like this?” He hugged

me the way only he can and replied with tears in his eyes: “More than you can imagine.” Six months later, I found out I was pregnant. I told Marian with tears in my eyes. He hugged me, kissed me gently on my forehead and said: “Barbi, I love you. We can manage this.”

All the examinations were good – rheumatology, nephrology, blood pressure. The doctors recommended an amniocentesis. Even though I was worried, everything turned out well. But in week 21, I suddenly experienced great pain in my lower abdomen, my head was spinning, my blood pressure sky rocketed. The doctors suspected I had a helicobacter infection and proceeded with gastric fibroscopy without calling in a gynaecologist. When Marian came to the ER he demanded that the doctors call a specialist. They immediately took me to the operating theatre where they had to terminate the pregnancy. I had something called HELLP syndrome. After a few days, I finally made it home, with wounds on my belly and even greater wounds in my heart. Even then, my boyfriend did not give up on me. When I was able to talk about my feelings, he suggested: “Let’s adopt a baby.”

Such words coming from a man? Yes, he said that. We started getting all the certificates together and attending the meetings. I did not focus on waiting for that one phone call; I started working as a nanny for a friend. We didn’t even notice how fast the time flew by. A year

and a half later, we got a call from the hospital that they had a beautiful and healthy new born baby for us. He didn’t even have a name yet.

Do you recall when I said at the beginning of the story that everything that has happened has a purpose and that it should have been like that? I really believe that. But let’s move a few months forward. When Marian (we didn’t have to think long about the name) was a few months old, my grandmother passed away. She left a large vineyard behind, with no-one to take care of it. Today, the Bibo Child Centre stands there. Bibo was the name of my husband’s dog – an American Pit Bull. My son loved him and so we decided to call our centre after him.

“I’m strong and I fight them”

I have read that one shouldn’t fight one’s illnesses, but learn to live with them. I believed that for a long time, but today I’m strong and I fight them. Naturally, I follow the treatment prescribed by the rheumatologist, but I’ve changed my lifestyle, diet and, above all, the way I think. And I’m here! Strong and full of life, with challenges and ideas that I would like to see to the end.

At first, I wanted to title this essay with something unusual. “Never happy”. But two men came into my life and they have made me the happiest person in the world.



Marian has always been our joy

When dreams come true
Barbora Fartelová



A party in our kindergarten



Alenka Hlebec
Slovenia



Taking pictures for my travel blog



Travelling is my motivation to keep on top of my RMD



With planning and preparation almost everything can be achieved

Give us a chance

I live between Trojane and Kog pri Ormožu in Slovenia, where my extended family also lives. I am 36 years old and work for the largest Slovenian insurance company where I manage social media and work in internal communications. My love of travel, photography and writing is reflected in my travel blog called "I Travel, Bitch".

I learned about this competition on Facebook and decided to share my professional story to help people with rheumatic and musculoskeletal diseases (RMDs) see that such a diagnosis doesn't automatically mean the end of a professional career.

I'll never forget the day I was diagnosed. The months of uncertainty were finally at an end. It was the end of hoping that this was just a temporary thing. It became clear that this was it. Everything changed in an instant.

I was 26 years old. I'd been employed for just over two years. Everything was ahead of me. My whole life. I had dreams, plans, hobbies and a lifestyle that suited me. I had the money to live that lifestyle with ease. My career was promising. My life seemed to be moving ever upwards. I was not going to let the pain that had started to torment me put a stop to this. I could do anything if I worked hard enough. All would be well in the end. I would overcome. Coming to terms with this was extremely difficult and something within me was broken forever.

For a long time, I could not accept what was happening to me. My head was firmly in the sand. I tried to forget and ignore it all. I tried to live as if

nothing had happened. It worked for a few years. Right from the start, it was difficult for me to talk about my diagnosis and my problems. I was ashamed. My family and close friends knew what was going on.

"I did not want to listen"

Eventually, I told my colleagues as well. They were all very understanding and empathetic. That was a huge relief. Then a new flare-up occurred and there I was back at the start. I was back at the bottom with a new rheumatologist and new medication. At least that is how I felt at the time. I was on sick leave for 14 days. The rheumatologist advised me to start thinking about the future with respect to my work. The stress affected my health even more and this was the first time we discussed part-time employment. I did not want to listen. A few more years passed in this way. Ironically, my biggest difficulty was coping with chronic fatigue rather than with pain or impaired mobility.

The topic of going part-time came up a few more times during my visits to the doctor. I did not want to listen,

even though I work for a company that enables this. The problem did not lie with my colleagues or line managers; I was the problem. I was ashamed of not being capable. I was in my early 30s and was incapable of working an 8-hour day. When an opportunity arose, I switched fields within the company and took on completely new responsibilities.

At my job interview, I explained to my managers that I have rheumatism. Nevertheless, they accepted me into the team despite knowing there might be complications or absenteeism. They accepted me knowing about my diagnosis and my limitations, and made me part of the team. This is something I want every person with rheumatism to experience. I want everyone to be given a chance to show what he or she can do and to be included. I want them to have that feeling. I want them to know what it feels like to be kept in the game even after having been dealt a bad hand – and to be given a chance to keep playing despite that bad hand. I want them to have the chance to learn new things and develop their career despite the risks that are associated with patients who have chronic disorders.

“It gives me the strength to carry on”

Of course they ask me if I can cope. If I cannot, I would be able to say so openly. And I am sure that they would help me if they could. Having open conversations and being treated as an equal is what gives me the strength

to carry on. Of course my work is very demanding mentally, but I do not have to worry about being sacked even though I work shorter hours. I am also happy that I have opportunities for further training abroad, that the company invests in me despite my disability, that I can live as normal a life as possible rather than eking out an existence on the margins of society.

I can also focus on my two passions: travel and photography. All of this helps me to cope better with the problems of a chronic disorder. It gives me the motivation to keep going.

Maybe I will not reach the very top of my career. Maybe I will never attain a salary that will provide me with a carefree life. I may have to retire early, far earlier than my peers, on a disability pension. Maybe, maybe, maybe... When will that be? How long can I continue to work and travel as I do now? To live without relying on others? I don't know... Maybe until death. Or maybe not. Maybe it will all happen much sooner than I expect. I don't know.

Come to think of it, nobody knows how much time they have been given, how long they will stay healthy and live the life they want. This is the essence of life: we do not know. Anyone's life can change in an instant. Everything can change in an instant. No longer being able to work full-time. Having to accept a new reality, new challenges. Having to accept that life has changed forever. Needing to live in the here and now.

This is why I want to be heard. I want to be given a chance. I want to be educated and to be able to advance. I do not want to be pushed aside simply because I have a chronic disease. I want acknowledgement that even part-timers can weave their thread into the tapestry that forms the company. I want a business culture to develop which will recognise, use and help to develop each individual's talents – even if this means more flexible forms of work, such as working from home or part-time employment. I want a culture that is empathetic and understands the broader picture – namely that, over the long term, the longer that we patients with chronic diseases work, the lower the cost to society, even if we only work part-time.

“We are not a burden or just a cost”

Have you ever considered how much energy and creativity a person with rheumatism invests into living their life as normally as possible? How creatively they face the challenges that confront them? Have you ever considered how much these skills can help work teams and companies as a whole, provided a company knows how to use them? I think that the company in which I work is succeeding in this and I want there to be more such companies.

I would like it if society as a whole, companies and the governments of the countries in which we live understood that, over the long term, we save by

ensuring that chronic patients have jobs and incomes. Because, that way, we are not a burden or just a cost. By giving us a job and work, companies are not being charitable because we do actually work and pay taxes. We are citizens like everyone else with special (additional) skills. However, it is true that we are more vulnerable – just like mothers with young children, older employees or disabled people. This is why we need legislation to protect us. Legislation that will protect everyone who finds themselves in such a situation because, ultimately, life is just unpredictable.

The world has become small, digital and flexible. Let us walk in step with it and start looking for opportunities and new ways to include chronic patients into work environments. Let us be the heralds of change and evolution. Let us seek solutions hand in hand so that every RMD patient can share my experience of working with people who give you a chance regardless of your diagnosis. Let those people be like my co-workers and supervisors who enable me and encourage me to develop my talents and educate myself, and who never make me feel superfluous.

I, too, contribute to the success of the team as a whole even though I only work part-time.



Working for the largest insurance company

Give us a chance
Alenka Hlebec

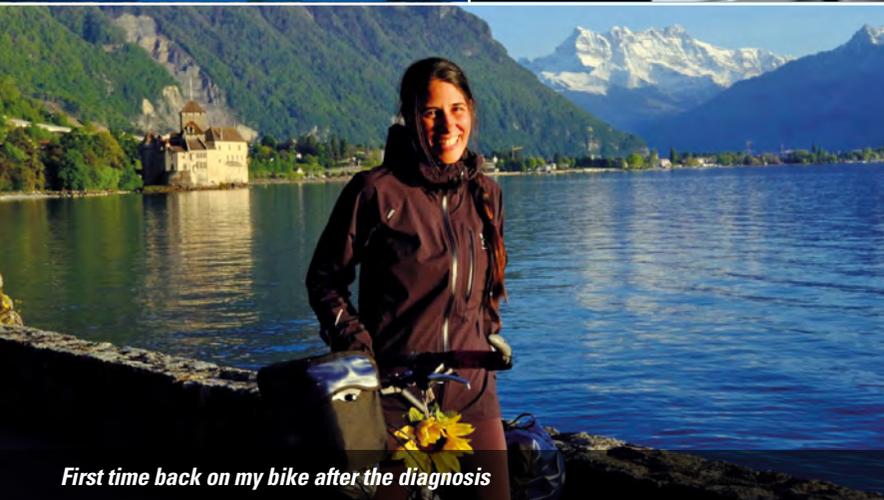


I love travelling and photography



Laetitia Masip
Switzerland

Talking about my life with AS and my bike tour at a conference in Lausanne



First time back on my bike after the diagnosis

By my side

I am 36 years old, married and live in Lausanne, Switzerland. I work part-time (30 per cent) as a bicycle courier. Previously, I worked as an administrative assistant, a manager of the gemmology department at a high-end jewellery store and as a bicycle tourist guide abroad.

I heard about this award last year when I registered to attend the EULAR Annual European Congress of Rheumatology in Amsterdam.

Since my diagnosis, I have actively raised awareness about ankylosing spondylitis. I feel that participating in this competition has allowed me to combine my commitment to rheumatic diseases with writing – a passion I have cherished for years.

What if my employer also suffered from ankylosing spondylitis (AS)? Sometimes I catch myself thinking just that. Would it make things easier for me and for all the other people struggling with rheumatic diseases if our employers faced the same struggles? Every now and then I wonder... Especially when I try to find my place in society with a disease that is still so unpredictable.

So, would a patient suffering from the same illness make the ideal employer? I honestly don't know. Maybe. But I have often wondered. Sometimes I think that, yes, they would. After all, it would be easier for them to understand what it is like living with this type of disease and the difficulties that it entails.

Trying to explain what it is like living with spondylitis is as difficult as trying

to understand why I am affected with it. That is why, for now, I think an employer who was also affected would naturally understand me better and be more compassionate.

"The disease is anything but coherent"

They would understand what I'm going through without my needing to explain it coherently, because the disease itself is anything but coherent. And when I explain what I need because of my disease, they might understand better. But, most of all, they might just offer me the opportunity to work and develop within my professional role.

All of this has led me to think that my ideal employer would actually be... myself. After all, who can understand my situation better than I can? Who knows my needs and the implications of my disease better? So, after my diagnosis, I clung to the idea of becoming my own boss for a while. After all, there was no one better than myself to adapt to the person I have become. But, although it was an interesting

idea, it was not what I wanted to believe. I considered it carefully but, in the end, I realised it was not really the ideal situation for me.

At the end of the day, what is an “ideal”? Is it something we dream of that we believe is difficult to attain? Or a situation that perfectly meets our needs... just as it should? My deepest wish is not to get over these obstacles, but rather to integrate them and, ultimately, transform them.

As Victor Hugo once said: “There is nothing like a dream to create the future”. With that in mind, my ideal employer is simply a future company where these obstacles are part of the normal course of events. So what I need to do is live in the now – as a person eager to work as well as a person not affected by ankylosing spondylitis.

“Every morning I wake up and choose to face my demons”

Above all, I truly hope the number of people affected by spondylitis – and all other rheumatic diseases for that matter – decreases, and that an employer who is not affected sees me for who I really am. That the employer sees my motivation and skills and, above all, realises I do not let my so-called “weaknesses” prevail over my strengths. On the contrary, every morning I wake up and

choose to face my demons. I fight to live my life despite my disease and to find my place in society. I try to give myself the means to thrive and I look around to see which resources others have made available to me.

I want to believe in a society where people affected by disease can work hand in hand with people who do not. That they might understand, encourage and support each other. And that they might shape the future together and be a force for positive change to create a world where the ideal employer is quite simply... an employer.

“Such employers already exist”

That is my ideal employer. Fortunately, such employers already exist. But I hope there will be more and more of them. My current employer does not have spondylitis but, to my great joy, offered me the opportunity I longed for. I applied for the job with motivation and... spondylitis.

My employer knew from the very beginning what my limitations were, but also realised how motivated I am. Today, thanks to this part-time flexible job that entirely meets my needs, I have regained my self-esteem and I feel like I have re-integrated into society and that I am contributing to change.

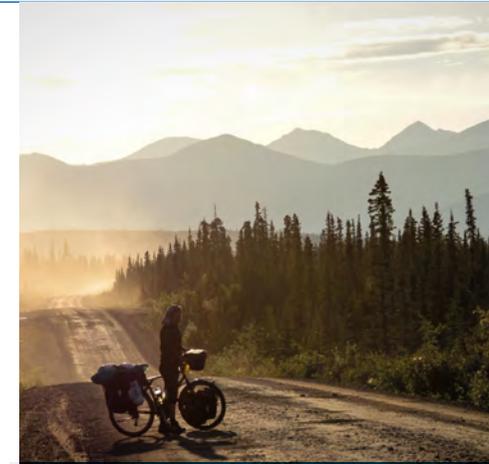
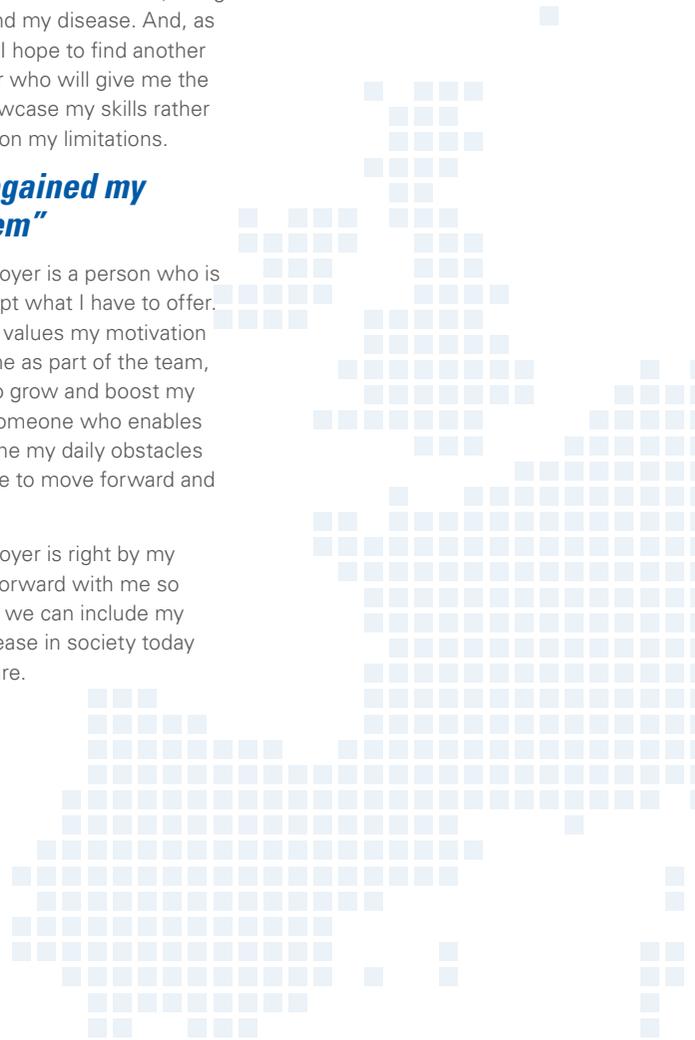
So, for now, I have found my ideal job and my ideal employer. I am an e-bike courier and I am integrated into a

team that accepts me for who I am. My needs will evolve over time, along with my job and my disease. And, as that happens, I hope to find another ideal employer who will give me the chance to showcase my skills rather than focusing on my limitations.

“I have regained my self-esteem”

My ideal employer is a person who is willing to accept what I have to offer. A person who values my motivation and accepts me as part of the team, allowing me to grow and boost my confidence. Someone who enables me to overcome my daily obstacles and pushes me to move forward and find my place.

My ideal employer is right by my side, moving forward with me so that, together, we can include my rheumatic disease in society today and in the future.



During my journey around the world by bike

**By my side
Laetitia Masip**



Meeting other patients with RMDs in Barcelona



Evidiki Ioannou

Meet the other essayists



Pauline Kreiken

Cyprus

Evidiki Ioannou
Larnaca, Cyprus

Lupus affects every aspect of my daily life, particularly my work and professional career. It's an area that, for me, plays an essential and pivotal role in the development of my personality, my good mental state, the growth of my confidence and my integration in society. I want and need to work because it makes me an active member of the society I live in, as well as with my family.

I also want to be a dynamic, strong, active woman — a role model for my daughter. I want to show and teach her that we do not give up when difficulties come up in our lives, but that we fight every day. We do not stop trying and we fight tooth and nail for a better life.



Brigitte Liesse



Elisabeth Schmeinck

Denmark

Pauline Kreiken
Svanholm, Denmark

Due to osteoarthritis of the spine, I was on sick leave for long periods at a time — I could hardly move without being in severe pain. For several years, the physiotherapist tried to make me fit in a suitable exercise programme as part of my daily routine. Half an hour of exercises every morning — a small price to pay to get rid of and prevent this hellish back pain.

After the first six months, the bouts of lumbago were less frequent, and the pain was not as intense as it used to be. It has been a year and a half since I last had a case of lumbago and resulting sick leave. Statutory sick pay is no longer required. My back is not completely flexible or pain-free, but now I can live with it.

France

Brigitte Liesse
Champigny Sur Marne, France

You would be the best of employers if you could arrange for me to work with older children, which would allow me to sit down for longer periods of time during the day. And if you could arrange for me to spend less time supervising the children outdoors. The thing is that I cannot stay sitting or standing for long: I need to move around. I would need to be given a classroom on the ground floor, because walking up the stairs causes me pain.

Please accept that I can no longer skip and jump around with my pupils, but I will gladly continue teaching them everything else. All I ask is for my workplace to be adjusted to my needs.

Germany

Elisabeth Schmeinck
Bocholt, Germany

I was promised all the help I needed to return to my job, whether or not my health insurance covered the costs of assistance tools at work. I made use of the right to cut down my working hours. The mouse for my computer was replaced and I was able to use an electric, height-adjustable desk. I felt that my colleagues were looking at my skills rather than waiting to pounce on any shortcomings that might arise because of the changes in my health.

When professional reintegration management is taken seriously and run by well-trained people, it makes it so much easier to return to work. It's a relief to be open about my illness. The energy you spend trying to hide it can be better used to maintain your health.

Meet the other essayists

Hungary

Jánosné Sípós
Miskolc, Hungary

I did not have an actual workplace, but I was able to work as a volunteer at a civil organisation. I had set up a work corner in my home with a desk, a computer, a printer, folders and the internet. It was a great advantage that I could work from home, do the chores and provide for my family. When my occupation grew too demanding and I got tired or was in too much pain, I could lie down and gather some strength to continue.

To me, writing is a joy and also proof that even rheumatic patients can have “soaring” thoughts, and that the lack of physical strength and limited mobility does not have to hinder the “freedom of the spirit”.

Italy

Daniela Quieti
Pescara, Italy

When I think of my “ideal” employer, I think of a positive, welcoming, impartial person who is keen on collaboration and willing to be flexible. I think of teamwork, motivation, empathy and productive exchanges with colleagues. Once you remove the social and architectural barriers that people with chronic rheumatic diseases face, you feel less disadvantaged – especially in employment.

That paves the way for innovative work models and shines the spotlight on the employee’s communication skills, goals and personal competences. When you have motor difficulties, every physical and psychological obstacle further accentuates your disability, causing even more hardship. The opportunity to work in an environment that guarantees dignity for all ensures equal rights to health and equality for every citizen.

Malta

Jane Giudice
Kappara, Malta

There is more value to a person than financial remuneration and it is highly noble to motivate less healthy people to contribute to civil society through voluntary work. For some patients, being gainfully employed is not an option but a necessity. In this respect, employers ought to give more weight and investment by providing ergonomic stations at the workplace, and providing more regular breaks to give time for a good stretch, moving around and grabbing some fresh air.

Wellness programmes ought to be introduced, offering nutritional and physical health facilities. A sick employee ought to be treated with the greatest dignity and respect. Offering more flexibility and the possibility of working from home is, indeed, gratifying to both patient and employer alike.

Norway

Marleen Rones
Rana, Norway

Having chronic pain impacts on our everyday life. In our daily life at home, at work, among friends and family, the pain is with us wherever we go – all of the time. Being in work is an important part of our identity.

When we meet new people, they often start by asking what we do for a living. Being in work creates a sense of belonging; we become part of a group or “one of the gang”. Belonging is hugely important to us as human beings, and it is one of three basic psychological needs we try to satisfy in our day-to-day life. But being in work also gives us a sense of self-worth: we are someone, we matter in some way, we can do something!



Jánosné Sípós



Daniela Quieti



Jane Giudice



Marleen Rones

Meet the other essayists



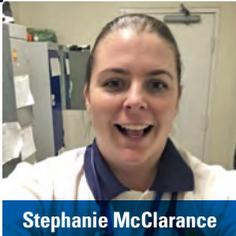
Maria Luisa Camacho Gonçalves



Ljiljana Jasnic



Annika Broberg Lavén



Stephanie McClarence

Madeira, Portugal

Maria Luisa Camacho Gonçalves
Funchal, Madeira, Portugal

My ideal employer is able to offer me a better quality of life, accepts me, respects the physical and psychological aspects of who I am and, therefore, also respects my limitations. I am fully aware of how debilitating this disease is. However, it is necessary to accept it and learn to live life with it as much as possible. Acceptance involves making adaptations and alterations to our lives. After all, isn't that what we have to do whenever an obstacle appears on our path?

My ideal employer makes an effort to know and understand my specific situation and seeks solutions to reduce the risk factors inherent to my profession.

Serbia

Ljiljana Jasnic
Veternik, Serbia

Empathy is an essential trait for someone to be called a good employer. I advocate we should not accept less; that we should fight for our rights. We can contribute to our society through work, hobbies and crafts just like everyone else! Maybe we cannot do something in the same amount of time as someone who is healthy, but give us a chance and just see what we can do.

Let us first work on ourselves and our self-confidence and, only then, stand before an employer and say: "Look, here I am. This disease is a part of me, but I love myself just the way I am. I have value, I am valued."

Sweden

Annika Broberg Lavén
Knivsta, Sweden

Over the years, my willpower has sometimes led me to bite off more than I can chew. In my enthusiasm, I have shouldered projects that, although I have been able to finish them, have been too demanding. Learning to calm down and listen to my body in order to conserve my energy is a life-long project.

I have been lucky that the response from others has been positive and understanding – that I have been able to work as my circumstances allow and not felt that I've received special treatment due to my rheumatism. As a result, most days I come to work with a smile on my face and can deal with tougher days with the help of my wonderful colleagues and supervisors – people for whom my rheumatism is not an obstacle.

United Kingdom

Stephanie McClarence
Epsom, United Kingdom

Unless we, as a community, feel safe enough to divulge what many of us see as "weaknesses", the prospective employer cannot make any adjustments for us and our work life will never improve. An employer needs to create a safe and welcoming environment to lay the foundations for a solid employer-employee relationship.

The best way to forge such relationships is for all to be approachable, reasonable, trusting, open and for the employer to not create a competitive "dog eat dog" working environment. We, the rheumatology community, may be at a disadvantage to those "healthy" individuals around us.

I feel a lot of us are held back by the "what ifs" and potential discrimination to be truly honest about what we need, as the world can be more focused on company profits than individual employees.



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