

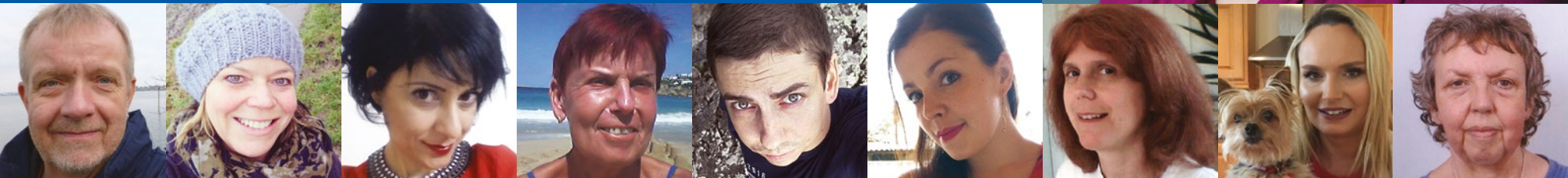
EDGAR STENE PRIZE 2018

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My personal champion

Supporting my everyday life with a rheumatic and musculoskeletal disease



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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 2018

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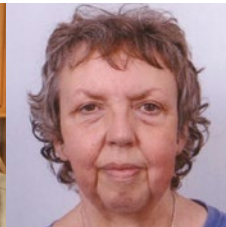
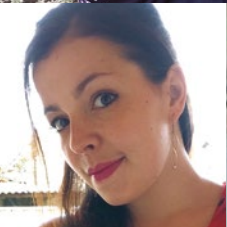
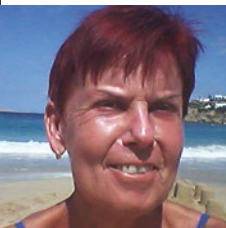
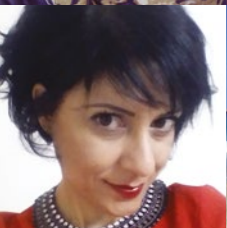
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Honouring our champions

It is with great pleasure that I accepted the invitation to write this introduction to the 2018 Edgar Stene Prize competition booklet. As a person who has lived with a rheumatic and musculoskeletal disease (RMD) for more than 40 years, I have witnessed and been confronted with numerous problems and obstacles.

EULAR unites the entire RMD community in Europe – the doctors, health professionals and the more than 120 million people living with rheumatic and musculoskeletal diseases. For me, EULAR is a champion itself – representing the tireless efforts of so many individuals who share their expertise, energy and time to improve the quality of life of people with RMDs through research and education as well as public awareness raising. As a longstanding patient representative in EULAR, I have worked to improve recognition of the severity of these diseases and worked to take measures to improve the quality of life of people with RMDs.

“My personal champion – supporting my everyday life with a rheumatic and musculoskeletal disease” has touched me at a personal level. We can see from the great number of essays – 20 countries participated this year – that it has also resonated with people from all over Europe. The topic is especially important for people with a chronic disease. Many times, they may despair at their daily struggle and the effort to face difficulties, pain, fatigue, exhaustion or helplessness. It is during these times that people need a hand, an embrace and a few encouraging words so that they keep fighting. It is during these times that each one of us has our champion or champions to bring courage, strength and a positive force. We continue with life, we face and overcome all the difficulties that present themselves, and each day we live our life to the full – with dignity and quality.

Each one of us has our own champion and these essays describe beautifully how they can be found in any place. Some are found in the face of family, in life-partners or friends, health professionals, co-workers or people with the same disease. Others describe their trust in life where perhaps their body, a hobby, their God or even hope can be their champion. However, equally important can be man’s best friends: animals. I’m sure that if the millions of people with RMDs in Europe were asked, their champions would not differ much from those in the competition essays.

The essays show that the daily struggles people with RMDs face are often simple things such as issues of self-service and daily tasks. But they can also be important issues such as educational problems or access to schools and work. And, of course, the more serious life threatening or life changing issues that some people face and must come to terms with. Through the essays you discover people’s determination to live, to create, to fight to cope with the disease and to live as normal a life as possible with no high walls and exclusions.

It is for this reason that the role of champions is very important. They support people in this life struggle; they are there to cheer up and strengthen the person to continue on, and to support them to live independently. In many cases the champion also takes the role of an informal carer. Informal carers are called upon to perform a social role, filling in the gaps and shortages of the state as far as care and support of people with chronic diseases are concerned. They must also be recognised and supported through various policies and programmes. The full social inclusion of people with disabilities and chronic diseases is very important, not just for the person and their family but also for all of society.

As well as bringing us a lot of benefit, our champions’ contribution to society in this informal way is immense. We owe them our unconditional appreciation and love.

I hope you enjoy your read.

Marios Kouloumas

EULAR Vice President, representing PARE (2013 – 2017)



The Edgar Stene Prize

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

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 co-operation 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.

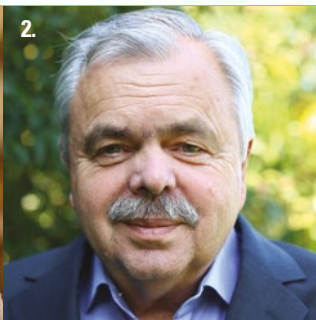
Rules of the 2018 Edgar Stene Prize competition

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 2018, entry was open to people with an RMD aged 18 years and over. Entries can be submitted in the native language of the author 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 cost of the winner attending the congress. In addition, EULAR will award the second-best essay with EUR 700 and the third ranking essay with EUR 300.

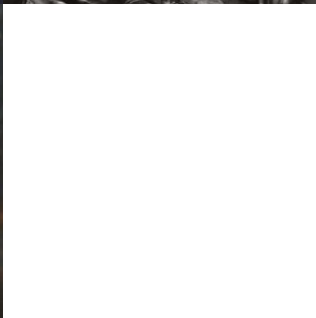
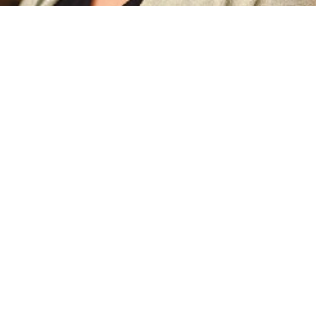
1. All quotes in the text are taken from the *Report on the Community Agencies presented to the EULAR Executive Committee and the Report from the liaison officer between community and professional agencies against rheumatism to the EULAR Executive Committee* (Zurich, 1973) by Professor J J de Blécourt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



The Edgar Stene Prize Jury 2018 — 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 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) and the EULAR Vice President, representing PARE 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)

"When I got my diagnosis, I was so lucky to have my family, especially my mother, to help me survive the first weeks. It is so important to have people around that can support you in difficult times.

I was really excited to read this year's entries about people's personal champions. They often have no idea how big a difference they make to the lives of people with RMDs. The stories for the Edgar Stene Prize competition contain a big, well-deserved 'thank you' to all these people who are making that difference."

2. Dieter Wiek, EULAR Vice President, representing PARE

"Being a patient with ankylosing spondylitis for more than 50 years, I have experienced different phases of illness in my life. I strongly believe that self-management and a collaborative approach with your rheumatologist, GP and physiotherapist enable the best coping strategy. But I have also experienced phases in my life and illness when I felt down and depressed, when I needed a helpful, considerate, supportive, trusting person. This year's Edgar Stene Prize topic 'My personal champion' exactly focuses on what we all need in addition to pharmacological and non-pharmacological treatment.

As a national jury member for this year's Edgar Stene Prize German entries, I was overwhelmed by the emotive experiences of people with RMDs. When reading these unique stories, I regretted that each organisation can only put forward one essay. But, I was all the more delighted to read the essays written by people with RMDs from across Europe."

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

"It has been a pleasure and an honour for me to lead the Edgar Stene Prize Jury. I have found it inspiring to learn more about how other people handle their daily lives with an RMD. The competition's topic is very interesting and important because all of us with RMDs need that 'personal champion' who helps us to move forward and look positively into the future.

As a member of a patient organisation for people with RMDs, and as a patient myself, I see many people who are champions themselves. But I realise that all these outstanding people wouldn't achieve anything without their own 'personal champion'.

This year's topic helps people with RMDs to learn from the experience of others and to start to value more what they already have."

4. Prof. Annamaria Iagnocco, Italy, EULAR Treasurer

"I am deeply honoured to have served as a member of the Edgar Stene Prize Jury. This prestigious initiative highlights different, crucial RMD topics from the patients' perspective and, for this reason, it is of great value to everyone who is a member of the rheumatology community and for all EULAR pillars.

This competition is enormously valuable and, in 2018, it is particularly important as it underlines the patients' feelings and their description about living with the disease. Working as a rheumatologist, I am involved in patients' care every day and I am certain that high quality of care is directly related to patients' opinions and experiences. When patients, health professionals and doctors share the stories from other patients with RMDs, quality of care is optimised – and this is the reason for the great importance of the Edgar Stene Prize.

I enjoyed reading the patients' stories and I am convinced that they will be an inspiration to everybody."

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

"Being diagnosed with a rheumatic or musculoskeletal disease, particularly at a young age, means a lifetime of self-management and the support of the important people in our lives. This year's topic stresses how vital it is to have a 'personal champion' behind us providing that support.

I was diagnosed with rheumatoid arthritis in my twenties, and I have my champions who have backed and supported me through what have been some dark and difficult days. Having learnt about my rheumatic conditions, I now manage them well, but I need the family, medical and other relationships to get through each day.

As a result, the pleasure and honour I felt at being a part of the 2018 Edgar Stene Prize Jury was immense. I am so grateful to have had the opportunity to read so many emotive and intensely personal stories which recognise the, sometimes, unsung champions in our lives who are all worthy of tribute."

6. Tor Eivind Johansen, Norway, 2nd Vice Chairman of the Norwegian League Against Rheumatism

"It has been my great pleasure and honour to serve as a member of the Edgar Stene Prize Jury this year. I have been inspired by the applicants' stories and their belief in the future.

The authors give readers an insight into their lives and the obstacles that must be overcome – and how people can adjust each day so that the disease will affect daily life as little as possible. You must be a champion every day!

I hope these stories help change the world for the better. They are very close to my reality because I have a wife with an RMD and a daughter growing up with juvenile arthritis. I became involved in the Norwegian League Against Rheumatism 25 years ago because of my daughter's diagnosis."

7. Dr. Yeliz Prior, UK, Member of the EULAR Health Professional Scientific Committee

"I was both pleased and humbled to be invited to serve as a member of the Edgar Stene Prize Jury this year. The competition highlights the importance of the involvement of patient and public opinion in the advancement of the treatment and research of RMDs. It also promotes co-operation between patients, health professionals and researchers.

Personally, I was overwhelmed by the quality of the essays submitted and deeply inspired by people's sheer determination. As a rheumatology occupational therapist, researcher and someone living with a rheumatic condition, I am passionate about supporting self-management. I know that the route to successful self-management is through a collaborative relationship between the person with an RMD and their healthcare providers as this will allow the person-centred goals to be achieved through evidence-based interventions.

I hope this year's essays help people to reflect on their own experiences and inspire them to go that extra mile to meet their own goals."

2018
STENE PRIZE
WINNER



Magdalena Misuno
2018 Edgar Stene Prize winner
from Poland



*Grzesiek, my horse
Akbar and me*



With my sister and mother

Learning to live with your disease

I am 37 years old, have systemic lupus erythematosus and live in Gdańsk, Poland. I studied classical philology [the study of language in written and oral historical sources] and have worked as a book and magazine editor and proof reader. Various life events caused me to become interested in human nutrition, so I started a postgraduate degree in psycho-nutrition. I would like to help others and will soon begin working in this field.

My life's passions are horses and horse riding. I love my daily walks with the dog, especially in the woods and by the sea. I am also interested in dog training, especially tracking. In my spare time, I enjoy reading traditional format books by authors like Grisham, Archer, Marinina, Pilch, Miłoszewski or Tokarczuk.

I volunteer at the Re-Misja (Re-Mission) Association and have been its chair for two years now.

I found out about the Edgar Stene Prize competition during a Polish national convention of organisations of people with rheumatic and musculoskeletal

diseases (RMDs). My motivation to participate was twofold. Firstly, I wanted to use my essay to thank the people who support me in my everyday life with an RMD. Secondly, I wanted to communicate to others – especially those who are alone or doubt their own strength and just accept the disease – that our present life, and our attitude towards ourselves and the world that surrounds us, is really up to us alone.

With what is in our heads and hearts, we can change our lives despite adversity, fate and the disease.

It is difficult to unequivocally declare who – or what – the champion supporting my everyday life with my disease is. If I were to suggest a person, I could not name only one. If I were to suggest something metaphysical, I also could not name anything specific. I do not believe in a god, and I do not follow any religion or cult of any person, creature or thing.

“What is attractive is inside us”

The champion is not even one particular animal. There have been a number of champions during the 16 years I have been living with the disease. Each of them has left a mark on me, consciously or not, leading me to a specific path and bringing me to where I am now.

When I was diagnosed with systemic lupus erythematosus (SLE) at the age of

21, the very first people who supported me then – and who have been supporting me all the time – were my parents and my sister. They have provided reassurance during difficult times, sometimes telling me off for being negative. They have shown me how to look for other solutions.

“They treat me as an individual, not just another patient”

Every day they prove that they love me despite the physical distance. They have given me the “tools” (as it is now commonly described, not only in professional jargon) to “manage myself”. This means that they suggest books, articles or films online which allow me access to the opinions and knowledge of others. They talk to me about life and what the most important things in our lives are.

Back then, another important person for a girl who went through a shock following her diagnosis – and who was wondering about what her life would be like (also her sexual life) and how she could be attractive with the disease – was her first partner. We met where else than at the hospital for rheumatic diseases. He – as well as other partners – proved to me that what is attractive is inside us, not outside.

It is not important what you may look like at a particular moment, if your joints are swollen and you cannot move, if your face and body are covered in red

blotches, your hair is falling out and you have bald patches on your head... What is important is your attitude towards others, what you represent and whether others want to be around you because of your sense of humour or what you have to say.

My main doctors – a rheumatologist and a haematologist – have also been my champions. Medicine really is their calling. I only found them a number of years after the diagnosis. They treat me as an individual, not just another patient. They know what works for me and what does not. They remember the bad times but also know what it is like when things are fine – and they do all they can to make that happen. I have cried in their offices many a time. They have always provided me with expert advice and not just empty consolations that “it will be OK”.

When the disease was particularly active, my rheumatologist would even call me to ask how I was and if the new medication was helping. My doctors have shown me how to manage my disease in medical terms. They have shown me that there are good times following the bad but also that, due to the nature of my disease, I must be prepared that things may get worse.

“Friends provide moral support”

My friends are also my champions. I can always confide in them when I have a dilemma – and I have plenty of those

because SLE is not just a physical, external condition. It also brings mood swings, constant uncertainty and anxiety or depressive episodes. Friends provide moral support. They visit me and console. It is incredibly important to me.

Random people I meet may become champions – sometimes unconsciously. Someone tells me a story which makes me think; someone does something nice which turns out to be of great help to me... Even people who are not friendly or supportive may turn out to be champions because we learn something from them, we draw conclusions. I also have such champions.

“Animals are equally my champions”

I said earlier that it is not only people who are champions. Animals are equally my champions: my dog, cat and horses. The dog, Huzar, is my personal trainer; he “tells” me every day that it is time to exercise. It is thanks to him that I can walk normally, that I am in shape and control my weight. Horses also support my fitness but are, equally, therapists for my soul. When pain would almost make my muscles and joints burst, when I was unable to get up on a horse alone, they would give me the most precious thing they could offer – the warmth of their back, their peacefulness and understanding. Finally, my cat Gremlina, a gift from my sister, knows when I am in pain and where it hurts. Her soothing purring and warmth make the pain go away from any given spot.

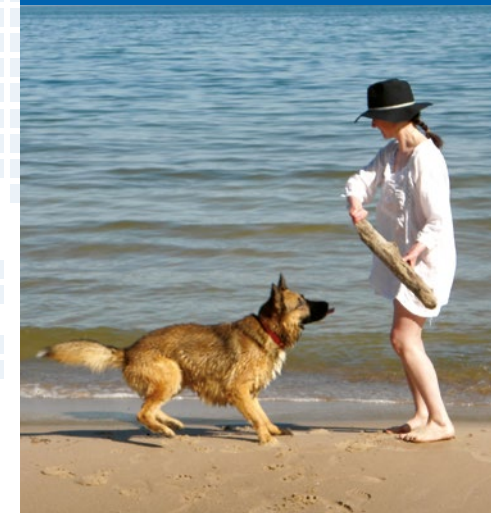
Lastly, my metaphysical champion is my own spirituality: my views and thoughts which I have developed thanks to the signposting of the above-mentioned champions.

We ourselves have to learn to live with our disease. People and animals may not be around forever. What we have learnt and received from them will remain. The most important thing is to learn to manage your disease, to know where to look for help and to teach yourself to access your own consciousness and tell yourself: “It will be fine. You know that.”



My mother

Learning to live with your disease Magdalena Misuno



Playing with Huzar on the beach

2018
STENE PRIZE
2nd place



Me, in September 2017

Here I am with the freight train



At the flea market –
on a bad day

Per Clausen
2018 Edgar Stene Prize 2nd place
from Denmark



A trip with my wife and dogs –
and packed lunch

When life changes track

My name is Per Clausen and I am 56 years old. I am a disability pensioner, but previously I worked as a mechanic. I have been married for 28 years, and I have two grown-up kids aged 19 and 21.

I live in Bramming in Denmark where I enjoy working around the house and in the garden, as well as making small trips with the dogs “into the blue”.

I saw the information about the Edgar Stene Prize competition on Gigtforeningen's website. I really felt like telling the story about how I overcame the toughest time of my life. Writing the essay proved to be good therapy. I cried but, in the end, a lot of things fell into place.

I was in the middle of my life when it happened.

It came sweeping in from a siding and hit me like a speeding goods train. It was as though an enormous, fearsome monster had mowed me down with a power that I didn't think it possible for a human to survive.

In fact, when I thought about it afterwards, there had been signals in my life of a future change of track, but I had ignored them. I had closed my eyes to the fact I needed help to manage more and more parts of my job as a mechanic. I had closed my eyes to the fact that I was becoming tired more quickly and found it more difficult to keep a handle on things at home.

I was in the middle of life and I wasn't ready to allow this to force a change of track.

To change direction – not now!

After many months in bed and in constant pain, after numerous visits to the hospital, and more medicines than I knew existed and could hardly understand, the judgement fell. A doctor, who believed that he was God himself, sentenced me without a thought to a life that I had no wish for! My severe pain would remain the same and I would continue to sleep my days away.

“My life stopped in an instant”

My life stopped in an instant. I stopped there in the middle of the track. Completely still.

Then the tears started to fall. I felt hopeless.

The walking frame, the wheelchair and other aids made their appearance shortly after. Cupboards and drawers were turned upside-down and reorganised to place things so that I could reach them more easily. The furniture was put up on blocks.

The daily struggle. My new me.

The role of father, spouse and employee all seemed completely impossible.

A work assessment forced me further onto my knees. When I was granted early retirement on the anniversary of my sick note, I felt nothing but distress!

“I had my personal hero completely by my side”

From day one I had my personal hero completely by my side, even though I wasn't aware of this at the start. From one day to the next she acted as my personal nurse, my case handler and my advocate.

In the evening, when the pain allowed it, we would lie in the dark. Even holding hands caused too much pain. So over time we learned to love each other without any contact.

My personal hero helped me to create a new identity. It was an identity without connection to the world of work. As the medicines started to have an effect, she challenged me to set goals, dreams.

We got a dog – a dog who could keep me company when she was at work. A dog that had to be looked after and taken outside. Slowly, very slowly, I developed more and more staying power and, one day, I could walk the dog myself. Making use of the

benches along the path where I could rest, I managed to walk almost an entire kilometre.

My personal hero ensured that I never stayed still on the track for too long at a time.

At Sano (the Danish Rheumatism Association's treatment centre), I retrained my leg muscles before receiving my first new knee. This was followed by a second knee and three knuckles.

My personal hero was a step ahead of me the entire time. She read about arthritis, read about exercise and about the latest research in the area. She reached out. Every idea just had to be tried! And most of all, she kept up hope!

“Every idea had to be tried”

Free physiotherapy and orthopaedic footwear helped me with my walking distance and speed.

An electric tricycle helped me get out into nature again and gave me a feeling of freedom. I could reach further than my legs could ever take me. This was her idea as well, and it was also the fruits of her work when the bike, after a very long fight, was finally granted to me.

My personal hero registered me with GOK (the Danish Rheumatism Association's Information Circuit) and

got me swimming in the local swimming pool. Over time, I started to function so well that I could also participate in the physiotherapeutic GLA:D (Good Life with osteoarthritis in Denmark) training!

“Over time I started to function”

We struggle daily in a fight to maintain my abilities. I exercise. She thinks up new ideas and finds solutions to the problems that arise.

I am now much better!

I can now do a great many things again, and my personal hero allows me to do these, even if I do them slowly. She also has to hide her concern that I'm overexerting myself.

This is just a little insight into how my personal hero has helped and continues to help me. Do I need to explain that my personal hero is my wife of 28 years?

Let me end by presenting myself. My name is Per and I am 56-years old. I am a father, I am a husband and I perform good work in the home every day. I am much more than my disease, which is severe psoriatic arthritis.

I stood still in the middle of the track six years ago. Completely still. But only until the shunter train connected!




Biking with our first dog in May 2016

When life changes track Per Clausen




At the beach on a good day – 1 year after the disease began


Me, now

2018
STENE PRIZE
3rd place


Not only does Concetta tame tigers, she also attracts unicorns



Maiken Brathe
2018 Edgar Stene Prize 3rd place
from Germany



The other champions in my life are my dogs

The importance of shared experiences

My name is Maiken, I'm 47 years old and I live just north of Hamburg in Germany. Because I've had polyarthritis in all of my joints since 1980, I am unable to carry out paid work, but I hold qualifications in German and journalism, and currently work as an author.

I'm a passionate photographer, Instagram and Facebook activist and, above all, I love living with my dogs.

I found out about the Edgar Stene Prize through the magazine *mobil* which is published by the Deutsche Rheuma-Liga. I like to write about my experiences of living with a chronic disease in the hope that I can help others to take a positive approach to their illness.

She ought to wear a red cape as she whizzes through Munich in her electric wheelchair, because Concetta is my personal champion. Anyone who has seen this superwoman would probably agree. It's hard to believe that so much vitality can be packed into a body just 1.46m tall.

I met Concetta over 30 years ago at a hospital for children with rheumatic diseases. I was 16 years old at the time and had been suffering from polyarthritis in all of my joints for years. It was at this hospital that I had learned to walk again but like all the other patients – children and grown-ups alike – I was struggling with homesickness. Concetta had just turned 10 and was much more self-confident than I was at the time. Her illness is extremely rare – juvenile dermatomyositis – and Concetta was dependant on round-the-clock support. Back then, I was very uncertain about how I should approach her because it hurt to see her in such bad health. But,

at the same time, I found it tremendously annoying that this little Italian girl stuck to me like a limpet, always wanting to know what I was doing, if she could come with me, if we could do something together...

"This was an important step towards independence"

Even if I sometimes rolled my eyes each time Concetta popped up in front of me, I understood that this girl wanted me to do something that I had never had to do before: care for somebody else. As I'd spent my life being the permanent object of care, this was an important step for me towards independence and becoming an adult. Concetta never asked herself whether or not I would be able to take care of her. And it took many years for me to realise that I could.

For over 20 years, we lost contact and developed independently into self-confident women who were able to finish their studies and find their places in the world despite being severely disabled and suffering from illnesses. But still, there was something missing. I needed someone who didn't need an explanation of how traumatising hospital

stays can be, how degrading it feels to be treated as an object in medical theatres, and how hurtful it can be sometimes when someone stares at you as though you're from another planet. Or how shaken you feel when a kid in the street unexpectedly mocks you with abusive words.

When I got a letter from Concetta in 2008 saying that she was organising a reunion for everyone who had been at the children's hospital for rheumatic diseases, I couldn't stop myself from crying. If I'm honest, I didn't think my annoying little friend would have survived because of the severity of her illness. After more than 20 years, we finally came face-to-face with each other once again – and, this time, it really was face-to-face despite a height difference of 26cm.

"Our reunion really touched me"

Our reunion really touched me. It was a crucial experience for me as it showed what was missing from my life with "healthy" people: exchanges with someone who shares the same experiences as me! Someone who doesn't need an explanation of why some days I can't open a door; someone who reaches for the sugar in a coffee shop with the same crooked fingers as me; someone who doesn't comment that sugar is bad for rheumatism and that I should watch what I eat because they've read it somewhere and are "only trying to help".

After that reunion we vowed to stay in contact this time. But, as is so often the case, the countless kilometres came between us. There are more than 900km separating Concetta and me and neither of us enjoys speaking on the phone. Holding a telephone causes a lot of pain in the hands and elbows. Speaking openly also means being alone, which proved nothing short of a logistical miracle for someone who requires 24-hour care and has an overprotective ex-partner. Then there was the task of finding a moment when neither of us was too exhausted to properly engage in conversation with the other.

But we managed to find the perfect alternative: for three years, we've been sending each other voice messages using our smartphones. Each day, we tell each other anecdotes about our daily experiences and, when we're feeling lonely, we sit together (virtually) at the dining table and listen to each other's news while we eat. Most of all, we're there for each other when one of us feels misunderstood, or when our fears of the illness and death loom before us like an invisible tiger roaming around the room. With Concetta, I talk about the tiger, give it a pet name and, eventually, tame it. Naming the fear makes it less scary for me.

I avoid speaking about this with the other people around me. Certain friends feel overwhelmed – most only show a certain level of concern then withdraw because they don't want to be confronted by the thought of illness.

When I was a child, my mother brought me comfort and took away the fear of death, softly whispering "everything will be OK". Then, once I became an adult, I understood that my mother's words were just a formula, because she wasn't in a position to be able to assess the situation. My mother passed away six years ago and, even though I'm now a woman in her 40s, I was still missing that one person who didn't need an explanation of my ordeal of living with a chronic illness.

Now I have my little friend by my side – well, at the other end of the country. I have Concetta to help me ward off my fears. The simple act of expressing my fears means I get to do a tremendous amount of self-reflection which helps me to collect my thoughts. Putting these thoughts into words helps shine a new light on everything and helps me to separate emotions from facts.

"She has the skills to conquer tigers"

Concetta is a woman who has been through a lot. She has the skills and experience to conquer tigers, evaluates the facts with me and helps me maintain an objective perspective on things. She consoles me, but not with the "everything will be OK" formula that has now lost its magic. In her I have found my confidante who is there for me at the drop of a hat, my lifeline, my own first aid kit. She says to me: "Maiken, don't lose your head about it, try to think clearly. I'm here for you

whenever you need me." And that's exactly what I need in the moment.

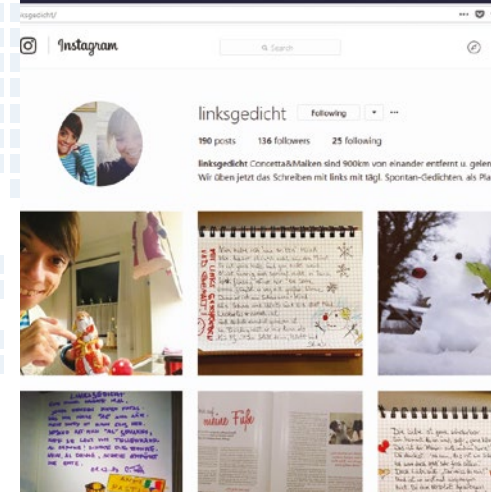
Concetta and I are like identical twins separated at birth – and by the stretch of Germany that lies between us. It doesn't matter that she's short and I'm tall, that she's from the south and I'm from the north. We became kindred spirits in our childhood as a result of shared experience. I call her my "journal" because she's been by my side through my fears and she's helped me through other troubles in life: separation, illness, moving, a new beginning. She calls me her "cortisone" because she needs a daily dose to give her the boost to get through the day. Together, we've developed a Plan B for our lives. We make jokes over Instagram, share these thoughts with others and show people that there's always a Plan B in life, even if we don't think we can carry on.

I'm a personal champion for Concetta too, a heroine of sorts, even though red isn't my colour. I still think they should make the cape in size "S" though. Because my little friend is so great and powerful, she can easily tame ferocious tigers and overcome 900km.



Concetta and I have been friends since 1986

The importance of shared experiences Maiken Brathe



Our Instagram project, "Linksgedicht", has even been mentioned in a magazine



Antonia Apostolou
Cyprus



Monday's guitar lesson



Getting ready for the MRI scan



September 2015 – cruising around Patmos island

Someone I can call my own

I come from Xylofagou, a village in the Larnaca province of Cyprus. I am 42 years old, divorced and I do not have children. I live in a small rented apartment in the village together with my little dog, my companion.

I work three days per week in the private sector as a clerk – just as much as is necessary to cover each month's expenses.

My rheumatic diseases make things very difficult for me, but I am doing my best to live as normally as I can physically endure. In the morning, I push myself really hard to get out of bed and get on with the daily requirements. I do not give up. I have a lust for life and learning. This year I took up guitar lessons, something that I had really wanted to do for many years. I keep going to the gym twice a week. Needless to say, my physical exercises are now milder and the time I spend on them less.

I first read about the competition in 2013 or 2014, through the very first magazine I received from the Cyprus League Against Rheumatism after becoming a member. This is the first year that I have found the courage to write. I guess I was inspired by the subject.

The “beginning of my sufferings” made its powerful and provocative appearance in the summer of 2004 after a separation. I felt intense fatigue – to the point of being unable to turn around in bed or move my fingers. Even opening and closing my eyelids took an effort. Let alone keeping my job which was very demanding.

Unfortunately, my “own” people were not there for me. There was not a single human to really care. No one had the time to get involved or at least to try to understand me. No one to ask if I needed something – something to eat, a hug – or just to say “I’m here for you” even if they did not really mean it... This too I fought on my own, as I had learned to do over so many years. Fighting for life on my own was nothing new to me. I managed, albeit temporarily, to stand on my two feet with a homeopathy treatment. I made

a new start, moving to town and making a new social circle.

“Little did I know that this new friend would become a pest”

Later on, I got married again with the illusion that the hard times were behind me, both emotionally and physically. Unfortunately, in August 2012, two of my “toxic beloved ones”, my husband and my father, gave me the final blow. The traumatic emotional shock caused by their arguing opened wide the door to my, since then, inseparable close friend who goes by a double name “fibromyalgia osteoarthritis”.

I did not recognise her immediately though. I felt tired, exhausted. My entire body was aching, but I told myself: “It is not serious, you are tired, it will be alright once you lie down and rest. Everything will be alright”. Little did I know that this new friend would become a pest, ferociously sucking me dry of all my energy.

It was on Wednesday 27 February 2013 that I was officially diagnosed with fibromyalgia syndrome by a

rheumatologist working in the public health system. This was after six months of endless symptoms and tests, starting from a pathologist and ending up with a rheumatologist. I did not want to believe it or accept it, so I made an appointment with a private rheumatologist. On Thursday 14 March 2013 this doctor also confirmed the chronic disease, adding her second name: osteoarthritis.

I do not remember how I managed to leave his office. What I do remember is that I felt the need to be completely alone in order to understand what exactly the doctor had told me. I went down to the beach, bought myself a cup of coffee and sat on a bench staring at the sea. I was tormented by my thoughts and the despair that I was feeling. I cried, sitting there in the cold afternoon wind. My soul was crying out for help. I was 37 years old and I had just realised that I had no one that I could call “my own” to support me, to hear me out. No husband, no family, no friend. Not even the slightest trace of concern.

“My inner pain was greater than the physical one”

My inner pain was greater than the physical one. How desperately I was in need of someone I could call my own. I cried, opening my heart to God, begging him to help me get through all the hardships that would be my companions from now on. It was a cold tormenting afternoon. It still hurts me a

lot, just like it did back then, to think that my beloved persons were absent by choice.

When I got back home, Sandra, my little beloved dog, my “four-legged daughter” who was not even three years old at the time, was there – faithful and saint-like, cheerfully waiting to show me her unconditional love... To prove to me, once more, that she was happy to see me, and to remind me that life has a bright side too... To minimise my pain and give me strength to carry on.

As soon as I recovered from the raw reality I was facing, I decided to embrace it and carry on. Although I had no human friend by my side, I was not alone since I had my faithful assistants by my side: God and my little dog. I am extremely grateful to them! It is thanks to them that I did not put an end to my own life in December 2013, when the despair and the pain reached unbearable levels. Along with them, I managed to escape the quicksand that was swallowing me. Without the strength that they gave me, I would not have been able to make it. Indeed, I came out stronger and more determined to live life as best as I could. I enrolled in a gym and took up guitar lessons. I found myself. I became a volunteer. I found joy.

In the process, completely unexpectedly and at the age of 39, I made a new friend. A human friend! A friend who chose to stand by me in every way she knew. A friend who deserves her title. Friendship means

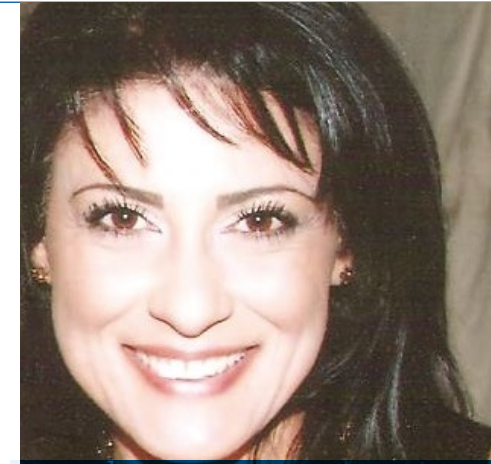
love. Love means to put your words into action. In her I understood what it means to be a true friend, not a superficial one.

“Love means to put your words into action”

Her assistance and support earned her the title of the friend of my heart. The friend who became my family, who became all the friends I did not have for so many years, the friend who chose to give her all just to see me happy, just to see me be well. The friend that I woke up in the middle of the night to take me to the hospital emergency clinic. The friend who held my hand when I was in the MRI scanner. The friend who drove an entire day for me, passing through two cities in order to take me to my medical appointments and be my companion during information meetings of the Cyprus League Against Rheumatism. The friend who brought me food and fresh juice. The friend who embraced my pain as her own. The friend who chose to be there for me, in bad times and in good.

Through this brief narration, I wish to express my gratitude to my three heroes, these three important persons in my life. My God, my dog, my friend. I want to tell them that I love them very much and that I am glad they are a part of my life, because they make a difference. They give me courage to keep on living and fighting. To keep on climbing my personal Golgotha – fibromyalgia and osteoarthritis –

focusing not on the pain and the awful experiences of my past 41 years of life but, instead, on the good things that I have and that I enjoy today. And on the hope for a better, brighter and happier future.



At a friend's wedding in Salonica in 2015

Someone I can call my own Antonia Apostolou



Summer holidays in Kefalonia – enjoying my beer

With my husband

Ivana Halouzková
Czech Republic

Holidaying with friends and their children in Sweden

The hero within me

I am 53 years old and live in a family house near Prostějov, a city situated in the eastern part of the Czech Republic. I have two sons and one grandson. When I was 30, I started to have symptoms of Raynaud's syndrome. When I was 42 years old, the doctors diagnosed scleroderma. Additionally, I have pulmonary aspergillosis.

I am a midwife, a trained health professional, but I had to stop working as one due to my sickness. I have also worked as an accountant.

I try to live a very active life. I always stay optimistic. I help with organising meetings for patients with rheumatic diseases. The reason I wanted to participate in the Edgar Stene Prize competition is that I would like to show patients that they can lead an active life.

My story started exactly 11 years ago when I went for a routine examination at the hospital's vascular department where I went for treatment for Raynaud's syndrome. My doctor suggested that I should go for a rheumatology check-up. A doctor welcomed me with a smile and, after a short interview, he took 12 blood samples and we agreed that I should come back in the morning for the results.

I came to the department with a smile, which quickly left me when the doctor gave me two pieces of news. The first, and worse news, was that I had an incurable disease that no one could treat effectively. The other, supposedly better, news was that the end would not come as fast as it would with cancer. The doctor diagnosed systemic scleroderma, a

disease I had never heard of and had never encountered before.

At the moment I went on the internet to search for information, my world started to collapse. I saw my two young sons, my loving husband and family, and I slowly began to say goodbye to all these. For one month I moaned in despair, deep in hopelessness, tears, bouts of depression, persecuted by the question "Why me exactly?"

"I started to fight with his constant support"

Sometimes during that time, my hero appeared to me. Thanks to him I took the rest of my strength and common sense, and I started to fight with his constant support. He told me that if I survived one month and nothing really substantial happened, I would still be alive and would have to rouse myself. I went into hospital for three months to have a lot of examinations, and it was only he who gave me the belief that I could manage it all and gave me the hope that I would get out of it and even encourage my closest family who suffered perhaps more than I did. He was the one who did not let me

collapse when my doctors told me that my throat and stomach were affected after gastroscopy and bronchoscopy, and when all of them showed positive results.

And then the biggest shock came. After lung diagnostic surgery, I was told that both lungs were affected by extensive interstitial fibrosis and were slowly losing their functionality. During my sleepless nights, when I saw myself suffocated by breathing apparatus, I wondered if it would get better. Everybody around me supported me as much as possible but, without him, I would never have found the strength to resist my fate.

So, I started to fight. First, I went back to the activities I was used to. I started to swim again, ride a bicycle, go for walks and gather all kinds of advice on how to help myself. Again, it was him who implanted in me the idea that I do not have to end with the most terrible stages of my disease that I had found on the internet, and he screamed at me not to give up and not to lose my faith. And only with him behind me was I able to support my two sons and gradually lead them both to graduation and the degree ceremony at which we, my husband and I, were very proud of them.

My hero began to push me and support me in my effort to find alternative ways of treatment, healers, rehabilitation and spa treatment. In particular, he reinforced my Aries stubbornness

which was given me as a christening present by my destiny. An Aries never surrenders and always fights.

“He suggested that I could manage on my own”

He accompanied me through all the examinations when the doctors shook their heads and compassionately looked away when they were forced to give me more corticoids and immunosuppressants. He suggested to me that I could manage on my own, that I could manage it all and continue to live next to my loved ones.

Even in moments when my work capacity was reduced and I collapsed with fatigue, he did not allow me to doubt that I could manage it. Perhaps the worst moments for me came when I first started to cough up blood, but he did not allow me to give up even at that moment. He stood next to me, encouraging me, saying that it would be better.

At my next examination, a serous lung infection was found that needed treatment with strong antibiotics for three months. Again, thanks to him, I endured the time when my liver collapsed – I was so tired at this point that eating only half a banana took all my energy and I lost 15 kilos. I survived the worst and, thanks to his support, I did not consider that it could have gone any other way than well. I stood in front of the mirror and he whispered to me – “Girl, you were

good, you mastered it. It is high time you started doing something again”. So, he took me out for a walk, slowly helping me to gain my strength and to start to function again. He did not let me down when I was depressed, even when they told me after CT scans that three months of treatment had not cleared my lungs and it would have to be repeated once again – this time for six months. He did not allow me to doubt or hesitate about the result, he just kept me in good faith.

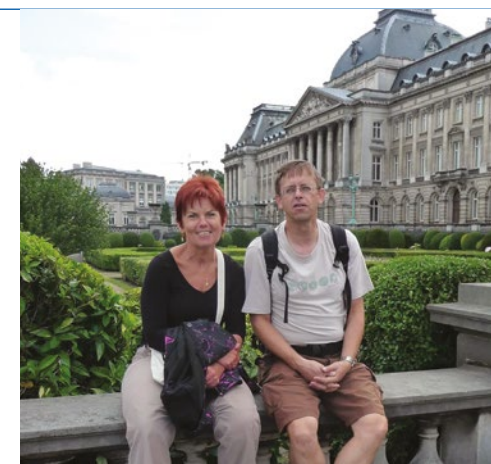
He does not allow me to lose my mind, to think what will happen next or if this treatment is not enough this time. He still makes me believe that it must end well and it will be good again, that I will have the strength to fight for myself and to support the others – the sick people who may be in an even worse situation than I am.

“I will have the strength to fight for myself”

He implanted in me the idea of sharing my bitter experience and fighting with similarly affected people, trying to show them that even with such great problems one can live a full and beautiful life. To support them in their effort not to give up and to enjoy every minute that is given to us.

I owe him not to try to think of myself as a sick person, and I’m always looking for a way to go on. How to forget and to dispel thoughts that can lead a person to the edge of despair.

And so, every morning when the alarm clock rings, I open my eyes and say: “Hero in me, get up and give me the strength to continue to live as I have till now. Hold me above the water and do not allow me to lose my faith!”

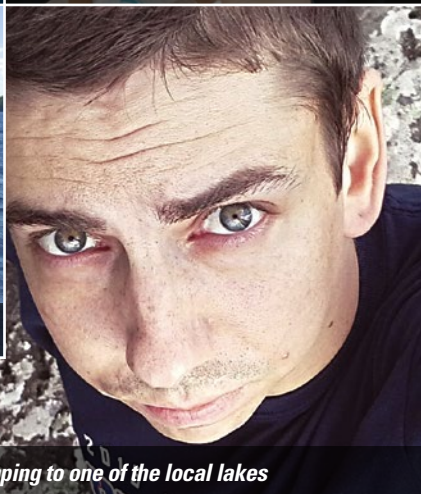


Sightseeing with my husband

The hero within me Ivana Halouzková



On holiday in the Netherlands



Thank you, Mother

I am from Sastamala in the Pirkanmaa region of Finland. I am 31 years old and, for eight years, I have worked as a salesperson in a paint store. I completed secondary education and studied painting at vocational school.

My hobbies include fishing and all kinds of sports. I also enjoy watching movies and TV. Music has been a life-long hobby and I have played in various bands since I was a teenager.

I was diagnosed with juvenile idiopathic arthritis (JIA) soon after I started primary school and suffered from it for some years. JIA was followed by more than 10 years of good health, but then I started having severe back pains. I was diagnosed with ankylosing spondylitis a few years ago.

I saw information about this competition on the Finnish Rheumatism Association's Facebook page. It was the first time I had heard about the Edgar Stene Prize. I had recently taken up my old hobby of writing – mostly about football. This gave me the courage to write

something for the competition. I wrote the whole text in one go, choosing to write it as a letter. I felt a need to sort out my thoughts about what has happened over the last couple of years.

Thank you, Mother. You have been my life's greatest support and safety. When I got juvenile arthritis as a child, I didn't really understand it. However, whilst being ill for years, all this became very familiar to me: blood samples, cortisone, hospital visits and physiotherapy. From this small town, we used to visit Tampere, the Tays Arthritis Outpatient Clinic.

They were always our trips and they felt safe. The rheumatologist and the nurse became extremely important and close to us. It was fun to take the trip as, after visiting the doctor, we always had a doughnut and lemonade in the hospital canteen. Often, during our trip, we also went shopping. We had fun which balanced our hospital visit.

"Is it catching?"

Due to arthritis, the wrist of my hand became almost immobile.

Its rejuvenation was started by a physiotherapist I knew. For school my hand was in a day splint, for sports in a sports splint and for sleep in a night splint. I remember when I had to give a speech in front of the class about my illness – I might have been in the third grade at school – and you became angry when the school principal asked afterwards: “Is it catching?”. It felt great that there was someone who dared to be angry with the principal.

You always defended and comforted your small and sick son. Therefore, I had the courage to join groups and sports teams just like anybody else. At times it was very painful. I will never forget what you always repeated when hugging me: “I wish I could take your pain and transfer it to me”. At times I felt that you succeeded.

“I involved myself in hobbies whenever I could”

Finally, the juvenile arthritis relented. For over 10 years there was no pain. Then, when I was approaching 30, it all returned. I stopped exercising: pain was in every part of my body. No one believed me. I was belittled by everybody: “It is part of your age, you know”. “We all have pain in our back”. You and I knew that all was not well. For two years I went through examinations and visited different doctors.

That period was really tough and distressing. Pain was affecting my every joint and yet I was working and

involved myself in hobbies whenever I could. First, the pain in smaller joints started to spread to the areas of my back and neck. For some six months I wasn’t able to sleep properly as I kept waking throughout the night, suffering from shocking back pains. Mother, I was very close to being crushed, but you, of course, knew that you were likely to be the only one who actually heard what I said. It was generally expected that we mustn’t be weak or complain. I have never understood it and neither have you.

Finally, as the last straw, I was sent for an MRI scan. I exited the tube wet with sweat and utterly shocked – my mild “confined space phobia” truly showed its power in the tube. However, a 45-minute horror film was useful! The visit to the Tays Polyclinic gave me the diagnosis that I was suffering from ankylosing spondylitis, which was active throughout my back, neck and thoracic spine. I cried all the way home. After two years I had found the reason for my pains. On the one hand, it was a relief; on the other hand, arthritis was again a part of my life. All the juvenile arthritis period was flooding my mind. In the first instance I, of course, phoned you. Who else could it have been?

I was administered a new drug using a fast timetable – a drug which is administered as an infusion therapy by hospitals. The treatments started to work! During all this time I have had a large network as I have managed during my short life to obtain a large group of

friends. My father and my siblings also have been involved in this. But you, my mother, have been the one who, at all times, lived with me and my illness from when I was a child. You remember my medical history by heart. Pain and anxiety are no strangers to you either. You know how I feel.

“When storms are raging inside, they have to have an outlet”

I have often vented my frustration and irritation on you. It always feels just as bad, but you understand. When storms are raging inside, they have to have an outlet. This is part of the illness image. I am really lucky to have such a large support network headed by you. I am really lucky to have family and loving parents. I know that it has not been easy to deal with me, and not just because of my illness – as if it wouldn’t have been enough! I am really lucky to have a mother who knows how to remove and understand some of my pain.

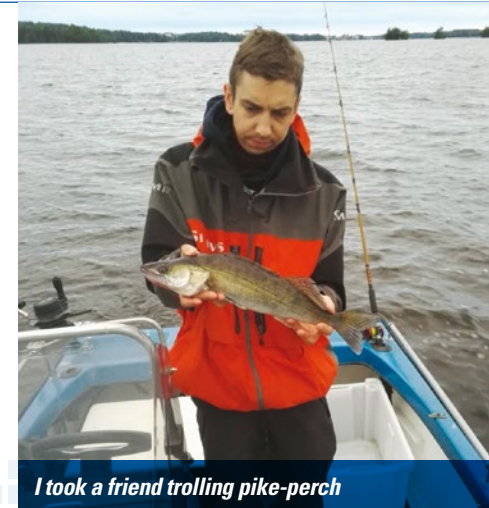
“I’m not able to describe how important you are to me”

I will never be able to thank you enough as there are no words for it. I am not able to describe the feeling of how important you are to me. When you phone me, interrupting a film I am watching, I may answer your call sounding tired, just wishing to carry on watching the film. But remember that I always have the

biggest compartment in my heart for you. I also hope that this letter, devoted to you, will touch others reading it. Our bodies are weak but, however deeply the pain affects our minds, we can have some control over it. That is where you listen, you try to understand, and are present and irreplaceable. It is a tough role, but it tells me that somebody cares.

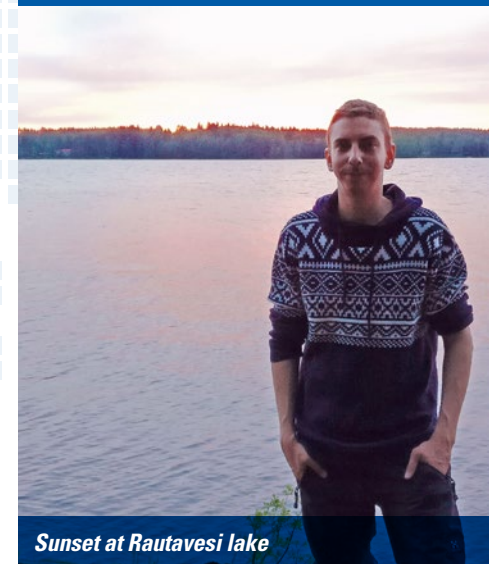
Thank you.

Olli Mäkelä



I took a friend trolling pike-perch

Thank you, Mother
Olli Mäkelä



Sunset at Rautavesi lake



Emilie Cazal
France



At the Rallye Aïcha des Gazelles



With my mum in the Moroccan desert



Mum and I having fun at the Cap Femina rally

My Mother, the hero

I was born on 30 June 1987 at Courbevoie in France. I have been a midwife since 2011 and I recently qualified in obstetric acupuncture.

I have spondyloarthritis which was diagnosed in April 2012. It mainly affects my sacroiliac joints. I love car rallies, off-road driving and travelling. I have taken part in several rallies, making several dreams come true. I practise meditation and am interested in alternative medicine.

I read about the Edgar Stene Prize competition in *Bouge ton Rhumatisme* – AFLAR, the French Rheumatism Association's, magazine. I wanted to enter because my relationship with my mum is of real support to me through my life with the disease. I immediately thought of her, of our mother-daughter rally and of the morning when the words "My mother, the hero" came into my mind.

My name is Emilie, I'm 30. People say that I radiate energy, vitality and that my smile makes them feel good. For me, life is exciting and full of special moments.

Six years ago, just after I qualified as a midwife, I woke up feeling as if someone had suddenly, violently thrust a scalpel into me just below my left buttock. It cut deep into my body and, if I made even the smallest movement, pain shot down my left leg. I had just started working and had a "show must go on" attitude. So, for nine months I put up with this scalpel every day: severe pain in the morning and even worse at night. I decided that irony was the best approach – "It will get better" – but the pain had decided to settle in properly.

It was some time before I could put what was happening to me into words and it was a while before I realised I might be ill. I was Emilie, the life and soul of the party, the class rep, the organiser of fun nights out. I loved dancing, singing, travelling, walking,

cooking, chatting with friends. I found that I could no longer walk guests back home, couldn't run, couldn't wear my heels. I would vomit blood after taking weird mixes of anti-inflammatories, thought well ahead before getting up from the sofa, woke up earlier in the morning because it took me an hour to feel better and clenched my teeth whenever I was on call and there was an emergency so that I didn't faint from the pain. I had to face the facts: "Mum, I think I have a problem"

"Every problem, my darling, has a solution."

In the end, I described the symptoms to my doctor who arranged for various tests and then gave me the diagnosis: axial spondyloarthritis (axSpA). I couldn't take in that I was ill. A number of options were open to me. I could wallow in self-pity, give in to the pain and struggle to stay alive, or I could follow my mother's advice: "You must take back control of your life, the disease must not dictate your actions – one day you will be able to do this"

"When will I get better?" I asked my rheumatologist. "You don't recover from

this disease,” she replied smiling kindly, “but in rare cases the disease becomes dormant, and that’s known as remission.” So, full of good intentions, I just replied: “I will be one of those rare cases”.

“Doctors would admit that I was strong and making progress”

When I left the consultation, I knew, not exactly when, but I knew that I would try to increase the number of pain-free days and that one day I would recover... The pain would fade, the treatments would work, and the doctors would admit that I was strong and making progress.

Three years ago, my mother took part in the Aïcha des Gazelles car rally in Morocco. At the age of 53, this was her first rally, her first challenge of this type. It took her a year to scrape together the money, a year of really hard work, negotiations, time, events and, finally, she fulfilled her greatest dream. Quoting the lovely words of Saint Exupéry in *The Little Prince*: “Turn your life into a dream and turn your dream into real life.” Mum, you’re so right...

I was stunned. My mother had done something entirely new in her life and had proved to me that “where there’s a will, there’s a way.” It may take time, it will require energy and courage, but we can make our dreams come true. When we reached the rally, I said to her: “Next year, mum, we’ll do this challenge, this

rally, together”. Although it’s a really tough event, she said: “If anyone’s going to take you into the desert, it’ll be me”. Together we decided to bury my disease in the sand, beyond the dunes.

I think you have to be slightly mad to take part in this sort of sporting event – and totally mad to do so with spondyloarthritis. Doctors don’t recommend that you shut yourself into a 4x4 and go off-road for nine days. But hey, why not?

From then on, I told everyone about my axSpA quite openly, without feeling at all embarrassed. I went on television, we reported on what we were doing, met with strangers, companies, patients, helpers. We organised the project, and the greatest victory for my mum and myself was that I was finally accepting the disease – I was no longer ashamed. Ultimately people don’t look at me any differently, although many think I’m mad to go off and take part in such a tough race with a disease like mine. But as I told you: “One day I will recover.” So, no, this challenge didn’t take away the pain – if only! – but it did score a great victory over the disease.

“We mustn’t let the disease get the upper hand”

The best thing that my mum says every day is that we mustn’t let the disease get the upper hand. We must live out our dreams as far as we possibly can. Helpers and, particularly, parents must

support their children and help them fulfil their dreams. Obviously, it’s often a great blow at first, but then we have to move forward and help our children, mum says – just like teaching them to walk. Parents should encourage them, support them and show them what it is to be in control of your life, not your illness. As you can see, her words are in my mind every day, every moment, stronger than the pain. They are sweet, sensitive, powerful words which help me to keep moving forward, as we have done together.

At the rally, an older and wiser friend of mine said: “Tomorrow, you’ll be saying ‘My mother, the hero!’ at the end of the first stage of the race.” She was right. I admired my mother’s mental attitude: she had decided to take me on an adventure, so that we could complete the various, increasingly difficult, stages together, to show me one thing: “every problem, my darling, has a solution”.

By sharing this experience with my mother, I learnt a great lesson – that life feels like an overwhelming gift whenever the pain subsides. I have found the strength to fight, to know that nothing is impossible. My body is not my enemy. I need to love it, wish it well. It’s in charge, but only a little. I need to accept my situation – that’s the biggest issue with the disease. It took me three years to speak about it, three years before I could write about it, share with others and be able to say that “I have axial spondyloarthritis. I’m

ill.” Just writing it brings a lump to my throat, but I accept it.

“I have a bigger smile than ever”

Life has its pleasures, joys and, sometimes, troubles. At the age of 25 you feel invincible and, if life hurts you – hurts you more than you could ever imagine – you still have a choice. You can give in and sink into despondency, enduring life as an invalid, or you can come to terms with it and live life as an invalid to the full, in whatever way you can dream up. Maybe I can’t go out dancing all night, but I can wait. In a few weeks or months, maybe I can go out dancing three nights in a row. If sometimes the pain disappears, one day it will be gone for good.

I now feel strong, determined and have a bigger smile than ever. After all, I’m lucky to be here, to have my mum. I’m lucky that, at the moment, I’m not in pain and can forge ahead, fight tooth and nail to fulfil my dreams. And, if the pain comes back, it will remind me that I didn’t miss it, but that I have to move forward, make the most of the days when it subsides. We have to love our bodies and, like two people in love, we have to believe in the future and throw our hearts and souls into it.



At the Cap Femina rally with my mum

My Mother, the hero

Emilie Cazal



Experiencing the Moroccan desert

*You can live without a dog,
but it is not worthwhile*



Eszter Rozán
Hungary



You can see the eternal loyalty in her eyes



A trip to lake Balaton

Lucy

I am a 48-year-old writer, journalist and bibliotherapist. I live in Szombathely, a medium-size city in the western part of Hungary. I am married, and we have a 15-year-old daughter called Zsófia (Sophie).

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

We are happy running down the hill. She looks at me every now and then, a bit worried, to check if I can keep pace. When I give her an encouraging nod, she keeps running with satisfaction. Nights are getting noticeably longer, the sun languidly smiles at us from up above, and rust-coloured tree leaves crackle under our shoes. These are all signs that we are getting closer to autumn. She waits for me at the valley. She doesn't dive into the creek until I catch up. She takes her time drinking cooling water. Then we continue our journey to the village.

Hiking with her like this seems to be so natural. However, it wasn't always like this. It wasn't long ago when our common journeys, even for a few miles, would seem like faraway dreams. Those who suffer from chronic diseases usually separate timelines into two sections: time before the disease and time after the disease. We had adopted Lucy before rheumatoid arthritis appeared in my life. She was only a few weeks old and was

curious and excited about occupying the house and the garden. She was interested in everything. Even when she tripped over her own legs, she would just continue discovering the territory enthusiastically. In particular, stairs proved to be a large obstacle — she rolled down them almost every day.

As she was growing, she and I set off for “pack” walks more and more often. Initially, we went only as far as the neighbouring streets, but we gradually increased the distance to reach nearby forests and towns. Eventually, we crossed the border and took some trips into Austria. My husband joined us on these walks whenever he could. We enjoyed sunshine, wind and, altogether, life.

“It was love at first sight”

Meanwhile, our baby Sophie was born. I was a bit nervous about how Lucy would react to her and whether she would accept that she would not be the only one in our life. I was afraid when I crossed the garden gate at our house. Lucy was running towards us with excitement — it was the first time that we had been separated for such a long time. She was curious to explore who the newcomer was.

“Lucy, this is Sophie! She is going to live with us.”

I thought Lucy would be jealous. It wasn't the case. Quite the contrary: it was love at first sight. She accepted right

away that our family had got a new member. Moreover, my daughter Sophie triggered some kind of parenting instincts in Lucy. Lucy would loyally stand guard as Sophie took a nap in her stroller in the garden, supervised her first steps and would not even think about leaving her alone for a second. They became true friends. We started to walk together. At the time, Sophie was sitting in her stroller instead of walking.

We seemed to have such a bright future ahead of us. I started university at the English faculty and had great plans about what I was going to do. However, this idyllic period did not last long. My dreams about the future were broken by rheumatoid arthritis. It came backhandedly. At first, I did not even take it seriously. After all, why would I care about some pain here and there or whether my limbs would need more time in the morning to catch up with the rhythm of the day? I tried to focus on the current tasks at hand. Nevertheless, there was a moment when I could not ignore its presence any more.

As we were walking down the hills by the Kőszeg Mountains, Lucy gave the leash a strong pull. I felt a terrible pain in my shoulder. Lucy noticed that something was wrong. She stopped and looked at me with solidarity.

"It's okay, everything is fine," I said to comfort her.

I thought that the pain would disappear in a few days or a week at the most. It had different plans – it did not go away or at least ease. On the contrary, it started to spread to other joints. I could not ignore it any more. It was time for me to take it

seriously and visit my general practitioner. At first, I was not shocked about the diagnosis. However, things changed when I looked it up in the internet where, of course, I was faced with the most severe cases: I discovered nightmares of paralysis and wheelchairs. "What is going to happen to me? And to my family? What now?" I was sitting depressed on the garden stairs when I noticed that somebody was licking my hand. It was Lucy curling up to me and looking at me with endless affection in her eyes.

I had a feeling that I had to pull myself together – for myself and for my family. I turned my head toward the coat rack where Lucy's leash was hanging. She got it straightaway and started to jump all over the place happily as I put the collar on her. Getting Sophie ready was not as easy – I could barely lift her up to put her into the stroller. I had to sit down for a few minutes to recover. Then we set off. We did not get far. Lucy was particularly happy and readily "replied" to the dogs barking from behind the fences. Sophie looked satisfied as she was babbling. One could smell the scent of lilac in the air. On that day, everything and everyone was blooming.

"I could not go any further"

And suddenly, I realised that I could not go any further. I felt unbearable pain in my ankle and sole. I had to sit down next to a fence. At that moment, Lucy stopped and started poking my knee with her nose. She wasn't impatient or trying to urge me. She was worried – like a dog who knew that something bad was happening. A friend of mine

approached us. He looked at Sophie and acknowledged how beautiful she was and how much she had developed. Then he looked at me. "Is there some problem?" he asked. "No," I replied straightaway. "I just got tired."

At the time, I was ashamed of my condition. I thought that it would be better to hide it from people. I got up immediately and used all my remaining strength to set off and demonstrate that I really was fine. I managed only a few steps but, luckily, my friend had already set off. At that point, the "pack" walks with Lucy came to an end. I could not care for my daughter or myself any more let alone manage walking.

Deep is never as deep as you might think it is. Even in the dark can be found a dim beam of light. I realised that having a disease was not at all a reason for feeling ashamed and that seeking help did not mean that we should feel exposed. I have had the pleasure of meeting a lot of helpful people.

Christmas was around the corner and I longed to see the Christmas lights at the main square. However, I did not stand a chance to get there on my own. My husband did not hesitate for a second. We got in the car and, in a few minutes, we found ourselves in the middle of the happy crowd. Lucy was initially a bit anxious having all these people around her, but the scents coming from the roaster booth helped to ease her mind. My rheumatologist helped to connect me with support organisations and the rheumatism association opened a new door to the world. I realised that I was not alone and

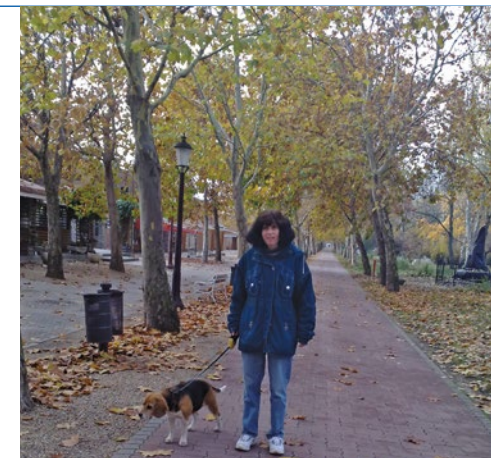
that if fellow sufferers stick together they may give each other strength.

"She was whining in happiness at the hope of returning to our old life"

And Lucy was also there. Even though we could not go for walks, which she acknowledged sadly, she showed the same affection to me that she had used to. When I had worse days, all she did was curl up to me and give me some of the warmth from her body. She was there when the disease appeared, and she was also there when my condition got better due to the biological treatment. On our first walk, her eyes were shining bright and she was whining in happiness at the hope of returning to our old life.

As the saying goes: "Living without a dog is possible – but pointless". The loyalty of dogs is not just a myth. They nurture unconditional love towards us as long as they live, and share our joy and sorrow. Like other dogs, Lucy, the Beagle, does nothing but give what she has. And even though dogs may not have everything in the world, what they give you might just mean to you all that matters in your life.

We are approaching the village where Sophie and my husband are waiting for us. This time, they did not come to the mountains. My daughter is smiling as she is showing the colourful leaves that she found along the road. Hand in hand, we walk on as Lucy is happy to be running around us and the soft autumn breeze is giving our faces a gentle touch.



Inseparable

**Lucy
Eszter Rozán**

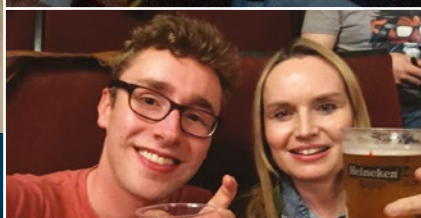


My husband with Lucy

My beloved dog

Siobhan Jones
Ireland

Declan with me in 1998



Sláinte! With Declan at the Caro Emerald gig — one of Dec's favourite singers



With Uncle Peter and his wife Betty in 2015

Doing whatever I want in life

I grew up in Coventry, UK until we moved to Galway, Ireland when I was 13. I am 42 years old now and still live there. My family is the most important thing in my life. I have one sister and three brothers – I adore my two nephews and two nieces. I am lucky to have extremely supportive friends with whom I always have a great laugh.

I love walking my Yorkshire terrier Elle on the beach. When I was younger I loved playing soccer and now play walking football with Croí, the west of Ireland Heart Foundation. Tattoos are a big passion of mine – I have several – and travel is another activity I enjoy.

At present, I am unable to work due to my condition. Getting my honours degree in social care practice has opened my horizons and I would love to continue my career, whilst working with people with disabilities.

I learned about the Edgar Stene Prize through Arthritis Ireland. I find journaling a great way to express myself and rid my mind of intrusive thoughts. Writing

this essay has enabled me to share my life experiences more freely. As I'm getting older I feel it's natural to share my life story with others who live with rheumatic diseases.

My name is Siobhan and I'm 42 years old. I've been unwell for nearly 20 years. I was diagnosed with fibromyalgia on 13 September 2007 – one of the best days of my life. In 2008, I was diagnosed with osteoarthritis and chronic fatigue syndrome. My life became easier after I was diagnosed – no healthcare professional will ever tell me that the pain I'm experiencing is in my head. I now had proof that I wasn't looking for attention; I had a rheumatologist tell me why I was in so much pain.

I was 17 years old when my youngest brother Declan was born and we've always had an extremely strong bond. Declan was six years old when I started to feel unwell. I was hospitalised often as every GP or consultant could not find out why I

was in so much pain. Every time I was in hospital, Declan would come and visit me, make me laugh and write me funny “get well soon” cards.

When I was unwell at home, Declan would watch MTV with me, singing and dancing to the music videos – some of our favourites were JLO, Sophie Ellis-Bextor and Backstreet Boys. The people I called friends at the time never came to visit me in hospital or at home. I know I would have taken my life if I hadn’t had my family to support me through the toughest battle of my life.

“For years I had too much pride to ask for help”

I feel that I participate more in society because of my brother. I now go to concerts on my own. Declan has taught me to speak up – to not have so much pride and to ask for assistance at concerts. For years I had too much pride to ask for help. I’d stand in pain and discomfort when there is an area for people with reduced mobility to sit. Now, I use my walking stick at standing concerts; people give me more space and they don’t push into me as much. I go to gigs or music festivals and sit in a reserved area with other people with disabilities. I can then sleep that night because I’m not in horrific pain and I can do more the next day. It has changed my life.

I’ve lived independently for over five years. When I’ve been discharged from hospital and I need help getting

around after steroid injections, Declan helps me with household jobs. He often stays at my house, even if he is at university or work. He is my rock!

Some of the best memories of my life have included Declan. We have travelled often together – Dec always helps me with my bags or mobility and he helps me live my life to the fullest. I travel every year to the UK on my own to visit childhood friends in Coventry and I go to see Coventry City Football Club play a football game. People stare at me as I’m a woman with a walking stick who likes football, watching a game where 99 per cent of the attendance is male. But, I hold my head up high because Declan has helped me to be confident and do whatever I want in life.

I play walking football every Wednesday with Croí, the West of Ireland Heart Foundation. The majority of people I play football with are over 50 years of age. As I have arthritis and fibromyalgia I am eligible to play. I never thought I’d play football again. I have made loads of new friends, no one takes the game too seriously and we have so much fun.

“I felt like the medical profession pushed my mute button”

I completed an honours degree in 2012. Declan encourages me to do my Master’s degree and a PhD and I’m in the process of writing a book about

my experience of living with a long-term health condition. Declan will edit my book when it is completed. Before I was diagnosed I felt like I had no voice – repeated hospital visits made me lose my voice as I wasn’t being heard. I felt like the medical profession pushed my mute button. I felt like I left my dignity at the front door of Galway Regional Hospital 18 years ago.

When our mother passed away in 2009, I was appointed Declan’s legal guardian. He was only 16 years old. During that period I often felt like it was “us against the world”. They say the death of a parent can break a family apart or make their bond even stronger. All my siblings and I became even closer. During that time, Dec and I helped each other to grieve.

Declan helps me keep informed about changes in technology and social media. We have spent many happy hours watching funny YouTube videos and Vines. Three years ago Declan found our uncle on Twitter. Our mother had lost touch with a lot of her siblings years ago. I’ll never forget when Declan called me and told me the good news. We have visited Uncle Peter several times in the UK and Peter comes to all our family events.

From a young age Declan would come to gigs with me. Most of the time he wouldn’t know the artist but he would always try to get an autograph, handing security a vinyl or a CD to get signed by the artist. With Declan by my side I got to meet two of my best-

loved music icons: Suzi Quatro and Cherie Currie, the lead singer of The Runaways which is my favourite band. With Dec’s help I have crossed many things off my bucket list.

“If you don’t use your voice, you will be forgotten about”

I’ve been on the social housing waiting list in Ireland for 10 and a half years. Every day I pray that I will get a phone call or a letter telling me I have a forever home. With Declan’s support I have contacted a local politician to help me find out how much longer I will be waiting. I felt like I had exhausted every avenue, so I contacted the Minister for Housing and the Minister for Disabilities. The old Siobhan of five years ago would never have had the courage to approach a politician for help. That’s because Declan believes in me. I now know that if you don’t use your voice, you will be forgotten about. The wait for my forever home continues.



With Declan at his Master's graduation in 2016

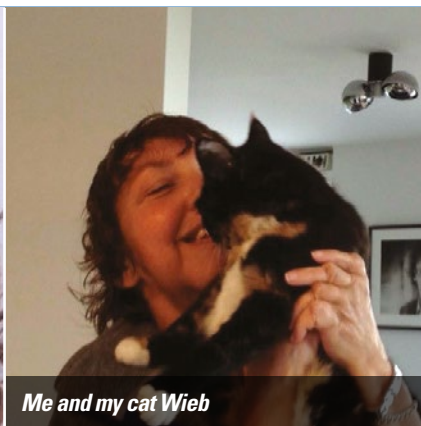
Doing whatever I want in life Siobhan Jones



Three coins in a fountain! Dec and I at Rome's Trevi Fountain in 2017



Emmie Willaarts
The Netherlands



Me and my cat Wieb



My pastime is drawing and painting



With sister Zus (left) and my mother

The trinity — from surviving to living

My name is Emmie Willaarts and I was born on 19 September 1961. I live in 's-Hertogenbosch, a pleasant town in the province of Brabant in the Netherlands. My mother and sister live nearby.

I turned 56 in the autumn and have had juvenile rheumatoid arthritis since I was a toddler.

I exercise under the guidance of a physiotherapist, something I really have to do because of my rheumatism. I practice Zen therapy, which is where I find my relaxation and my acceptance. I like to draw and paint, which also relaxes me and gives me satisfaction.

It is thanks to the support and love of my mother and sister that I succeeded and became the human being I am now.

I first read about the Edgar Stene Prize writing competition on ReumaZorg Nederlands' Facebook account. I then went on to read everything about it on their website.

It's Christmas Day 2017 and I can hear the voice of Antoine Bodar* on the television. He is saying: "You have to embrace suffering". "Yes," I think, "that's right." At the same time I think it's a good thing if you have people around you who embrace you.

My support is in the shape of a triangle, a pyramid. I can see it before me. At the top is my mother because, if she were anywhere else, the pyramid would be unstable. On one side of the firm base is my Sis. I'm writing her name with a capital letter, which happens automatically. Lying warmly on the other side is my great friend Wieb, who loves me unconditionally. When I lie down to rest my body, it isn't long before I hear her feline footsteps on my duvet. She cuddles up to me gently, licks my gnarled hands and makes the loveliest little noises. I couldn't wish for a sweeter pet to comfort me. Finally, I place myself in the heart of this loving pyramid. I feel

comforted in my suffering, my years of rheumatism which have left their devastating traces.

"The bond with my mother has always been a strong one"

I turned 56 in the autumn and have had rheumatism since I was a toddler. It wasn't until I was eight that the paediatrician dared to say out loud: "This is rheumatism!" My mother thinks I've always had it: "You were a difficult baby compared with the other children. You cried a lot".

I'm the third child of four in our family, and the bond with my mother has always been a strong one. She took me with her to places all over the country: to the country's leading rheumatologists for advice, to a naturopath who put me on a strict diet and injected formic acid under my skin until my back was bright red, and faith healers who intoned entreating chants over my head. She so wanted me to get better. But I didn't get better. I was chronically ill.

I had a difficult time at my primary school where it gradually dawned on me that I was different. I had leather tubes around my wrists to counter the deformities and I pulled my jumper well down over them so that my classmates wouldn't see them. Our teacher thought she could help me by unexpectedly pulling my jumper up and holding my arms in the air: "Has everybody seen it now?". I can still feel that overwhelming sensation of sudden nakedness. I wasn't helped or included; I was betrayed. Excluded. I had no idea how to defend myself.

"It gradually dawned on me that I was different"

I managed better at secondary school: I made friends, went out, had a life. I didn't talk about the fact that I was ill. I acted cool and tried to find my place that way. I had no self-confidence. How could I have confidence in myself when I couldn't even trust my own body?

Home wasn't a safe refuge for me at that time. My oldest brother and I didn't get on and he quickly found my weak spot. "Reumakip" was his regular cry. I had no way of answering back, in the same way as you can't answer back if you've just had a heavy blow to the head.

I've had training in various disciplines. I've always found studying fine – there was nothing wrong with my head. The obstacles came as soon as I had to set

out on the road to work. I couldn't cope at work, it was just too much. I wanted to do something with my life. I was looking for something that didn't make me feel so alone, I wanted to feel at home somewhere.

"I wanted to feel at home somewhere"

I needed help, someone to show me the way. That turned out to be Sis.

I joined a Zen group and followed a whole new road, the way to the inner me. What I have found there, with the passage of time, is that I have no limitations there – I'm not a rheumatism patient, just a person. It's also where I found my freedom again, which is certainly not unimportant.

"I started to make deliberate choices about how I would spend my time"

I started painting, I drew upon my creativity. At last I started to live and make deliberate choices about how I would spend my time, away from the unequal struggle that had so imprisoned me and that I was unable to defeat. I have rheumatism of course and, at the moment, I'm recuperating. I've had three new artificial joints in two years and, without the support of my mother and Sis, I possibly wouldn't have even entertained that. Everything leading up

to it, being admitted to hospital and the uncertainty – how would I cope? The difficulties started after the operation.

My mother is always there for me... A quiet presence, just as in this story... Modestly in the background but creating good feelings with her delicious meals every day and her companionship whenever I have to go to the hospital again. She does so even though she's also getting on a bit and gets up stiffly when she's been sitting down for a long time. Sis keeps an eye on everything, knowing exactly what's needed for me as well as for my mother. We have talked a lot with each other about my unhappiness, and tears are allowed at any time. The rheumatism has brought us closer together, and our bond has grown over the years from embracing the suffering to embracing each other.

I'm going to see where the cat's hiding, as the fireworks have already started outside.

* Antoine Bodar is a prominent Dutch Roman Catholic priest, professor, art historian and writer.



With my sister Zus

The trinity — from surviving to living Emmie Willaarts



Training at the gym with my therapist

Meet the other essayists



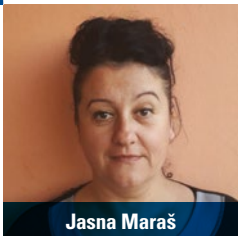
Petra Wegscheider



Ingrid Vandepaer



Miriam Greif



Jasna Maraš

Austria

Petra Wegscheider
Mariazell, Austria

It is so important to recognise and feel gratitude. I let my thoughts wander. I think of all the lovely people who have helped me through various stages of life – whether that be in school, during my studies or in the workplace.

I'm certain that listening, understanding and empathetic care are what bring us together. It's just a shame that only some people listen and help. My role models, my champions, bring these two characteristics together. So together, no matter how violent the storm might be, these people cast a ray of sunshine on my horizon.

Belgium

Ingrid Vandepaer
Kessel-lo, Belgium Flanders

His name is Art. He lives in my house, sits with me at the table, lies on my bed.

He walks with me in the street. Sees things that are there, as well as things that got lost. And sometimes a start of things that are still to come.

It is all ordinary. Maybe out of the ordinary, ordinary. But for us, ordinary.

To get out of there alive, I take Art with me. And that helps. I slow down when he starts moving the pencil. I play with the lines and let the time go by.

I take an empty page to do with what I want. I draw. That gives me space and freedom to become grandmaster of myself again. Thank you, Art.

Italy

Miriam Greif
Caldaro, South Tyrol, Italy

I dedicate this story to you, my body. My champion in everyday life. I want to celebrate you because you are with me through life's pitfalls, but I think about you very little. Thanks for your support, despite my pains.

You are my most faithful companion. You often go unnoticed by me because I pay more attention to you than I would like to when you do not work.

You are wonderful. Thank you.

Montenegro

Jasna Maraš
Podgorica, Montenegro

These two little beings, with life ahead of them, needed their mother. I did not want them to grow up without the most beautiful love, without a warm embrace and a sincere kiss.

"It's enough! This is not my life. This must not be my life!" Looking from this perspective, I swam in the dark waters of depression, maybe I would have drowned if they were not there, my two angels. They saved me, returned me back to life. They were – then and now – my protectors, my strength, my support in life.

I told myself that I will not give up; I will fight for myself and for my children... For all those who love me and whom I love. Everything else is irrelevant and unimportant.

Meet the other essayists

Portugal

Maria José Rosado Balão de Castro
Azeitão, Portugal

She doesn't know how much she inspires me when exhaustion strives to overcome me, when the pain insists on knocking me down, when depression lurks maliciously. Nor does she know how much good she does to my soul.

She is not present in my daily life, at least not physically. She doesn't visit my house, she doesn't put up with my depressive crises. She doesn't accompany me to my doctors' appointments, like my partner and my great lifelong friends (other heroes whom I honour daily). But I know that she is but an email or a message away. That she will answer me promptly with wise words of encouragement, that she will cheer my small victories with my students with a well-expressed text, or with a compliment.

Serbia

Ljiljana Jasnić
Veternik, Serbia

Because my champions are happy when I am Ljiljana who laughs. Because my champions are the saddest in the world when I'm not laughing. You see I'm not talking about one person. That means I am a rich person! I know you know I'm talking about my family. I don't have to deserve their love. I have two brothers and parents who would do anything for me.

When each of them hugs me, gives me a nice word — it doesn't hurt anymore. I did not want to put emphasis on the hard times we were having — and we have been through countless terrible situations. I wanted to say thank you. Thank you Jovan, Milos, mom and dad. Thank you for giving me the example of not giving up.

Spain

Cathérine Van Riel
A Coruña, Spain

Almost 18 years have gone by since my diagnosis. I have learned to fight my various health problems and, above all, to accept them and live with them.

I would not have been able to do that without the help of a number of heroes in my life. The closest to me, and the most important one, is my husband.

There are two more heroes I have to thank: my GP and my rheumatologist. Both of them always go out of their way to help me.

I consider myself very lucky despite my health problems because, thanks to my husband and the medical team who support me, I am able to have good quality of life.

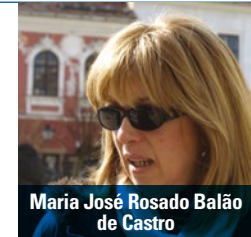
Sweden

Monika Wolfert-Rudborg
Strängstad, Sweden

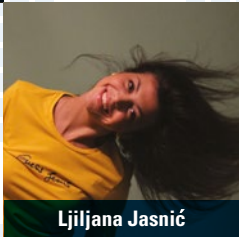
She is my hero in everything — large and small. My hero who makes me do the things that I never thought I would do. And who actually can, and does, laugh away the pain and fatigue sometimes. Who can look after me, help me and get me to go further.

She gives me perspective. No, I had never envisaged my life like this, but she helps me to see the possibilities. Sometimes she clowns around so that I laugh and forget the body I'm living in, and I see happiness and hope — I see my possibilities instead of my limitations.

We have our joint lives. We are moving forward together. We have our love for life and each other. We are one.



Maria José Rosado Balão de Castro



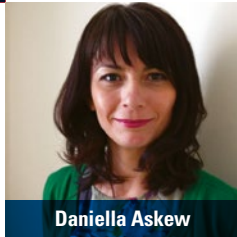
Ljiljana Jasnić



Cathérine Van Riel



Monika Wolfert-Rudborg



Meet the other essayists

Switzerland

Claudia Marchand
Selzach, Switzerland

How can I describe my champion? Perfect, but not in every way? Strong and weak at the same time? He is full of contradictions, but totally lovable. Granted, he has a few minor flaws, but it is still a miracle for me to have him and I am grateful every day that he is here with me. Despite a few limitations and some pain, life with him is just fine. We're a great team and we try to always look on the bright side.

I know my champion like a pilot knows his plane. Every alarm button has a purpose. Ours is an all-embracing, mindful, deep and trustful collaboration. We listen to one another and have faith in each other's abilities. And for this I would like to thank my personal champion, my wonderful body, from the bottom of my heart.

United Kingdom

Daniella Askew
Cheltenham, United Kingdom

I knew I could count on you when a specialised physiotherapist noticed something important early on. Whenever I saw her, I felt understood and that you were there; that there was a light. Although I couldn't always see it, she could and walked me slowly towards it.

You are found in greater supply on oncology wards, special care baby units, war fields and the make-shift boats of refugees, you are in the corridors of divorce courts and job centres. You are known by many names: goodness, mercy and faith. You are Hope — the promise of a rainbow. Without you we are lost and these events in life seem futile.



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