

# EDGAR STENE PRIZE 2017

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## Don't Delay, Connect Today:

Early diagnosis and access to care in rheumatic and musculoskeletal diseases – the ideal world and the reality



# eular

fighting rheumatic & musculoskeletal  
diseases together

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# 2017

***About Don't Delay, Connect Today!***

*Don't Delay, Connect Today!* is a EULAR (European League Against Rheumatism) initiative that unites the voices of its three pillars patient (PARE) organisations, scientific member societies and health professional associations – as well as its international network – with the goal of highlighting the importance of early diagnosis and access to treatment. In Europe alone, over 120 million people are currently living with an RMD, with many cases undetected. The *Don't Delay, Connect Today!* campaign aims to highlight that early diagnosis of RMDs and access to treatment can prevent further damage, and also reduce the burden on individual life and society as a whole.

# Contents

Introduction	4
About Edgar Stene and competition rules 2017	5
Meet the 2017 jury	6
Winning essay 2017 from the Netherlands	8
Second place essay from Denmark	10
Third place essay from Hungary	12
Selection of essays 2017:	
Austria	14
Belgium Flanders	16
Finland	18
Portugal	20
Slovakia	22
Spain	24
Sweden	26
United Kingdom	28
Meet the other essayists	30

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](http://www.eular.org)

## STENE PRIZE BOOKLET 2017

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# Don't Delay, Connect Today!

**I am honoured to have been invited to deliver the foreword to the Edgar Stene Prize Booklet. This prestigious publication from EULAR has been a yearly reminder to all of us – from physicians to policy makers – of how challenging it is to live with a rheumatic and musculoskeletal disease (RMDs).**

As one reads this year's prized essay – brilliantly written by Stefanie Hulst from the Netherlands – it becomes clear how society at large tends to undervalue what patients truly feel. Complaints of pain and discomfort are constantly ignored until, in many cases, it is too late to avoid a negative outcome.

As stated in several essays submitted to this year's competition, not only have many of those with RMDs tolerated excruciating pain during most of their lifetimes, they have also had to go through those difficult moments without knowing what was causing their suffering in the first place. To top it off, many have ended up being labelled as lazy or, even worse, as not being sick at all.

We have failed to put the patient at the centre of the health system and the direct consequence is the inexcusable delay of a proper diagnosis and of adequate care.

Thus, this year's EULAR campaign theme is a timely call to action directed to all of us: "Don't Delay, Connect Today!".

An early diagnosis of RMDs, along with timely access to state-of-art treatment, is a key factor towards a better prognosis and, ultimately, to a higher standard of quality of life.

This is particularly relevant when one knows that approximately 120 million citizens in the European Union, one fourth of our total population, present some form of RMD. The impact of these diseases on health and social services alone is calculated to be over 240 billion Euros, approximately 2% of the EU GDP.

Through scientific advancements, we are now fortunate to have medical technologies at our disposal capable of minimising patient's pain and suffering, allowing these citizens to be active and productive members of society.

In other words, with proper care, not only are we capable of mitigating the tremendous economic and social burden that RMDs impose on Member States across the European Union, but most importantly patients are empowered to live their lives free

from the shackles of disease.

Nevertheless, we still have a long path ahead of us.

A clear example of how we are lagging is the negative impact RMDs persistently have in patients' work lives.

The truth is that people with RMDs tend to have a harder time in getting or keeping a job. The indirect impact of workdays lost due to RMDs amounts to 650 million Euros per year. One in every three employees with rheumatoid arthritis leaves the workforce.

The right to work is a basic and fundamental right, as clearly stated within the Universal Declaration of Human Rights. To work is a means for self-realisation through which every citizen may achieve fulfilment of one's own potential. As proclaimed by the Europeans Patients' Forum, citizens that have access to work tend to be more productive, less prone to exclusion and lead more healthier and happier lives.

Society as a whole – including within the workplace – must drive towards preventing RMDs and slowing its evolution to avoid severe disability. However, the truth is that this is still far from being the general rule of practice.

Nowadays, there is no excuse for allowing people to live with RMDs in pain and suffering as generations of patients went through in the past.

We must listen and value what patients are saying, end all forms of discrimination towards people with RMDs, ensure that they are promptly diagnosed and guarantee that they have timely access to treatment and care.

It is time to act.

Don't Delay, Connect Today!

**Ricardo Baptista Leite**

Member of Parliament, Medical Doctor and Head of Public Health at Católica University of Portugal





# The 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 cooperation between doctors, patients and community workers”<sup>1</sup>.

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 2017 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 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 2017, entry was open to people with an RMD aged 16 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 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 2017 — 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 annual Edgar Stene Prize competition. This year we welcome our judges who represent the three pillars of EULAR, and who come from a number of 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. Dieter Wiek, Chair of the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (PARE)

"When I was 17 years old, my rheumatic condition hit me out of the blue. I consulted different doctors and clinics and my odyssey began. It took five years to get my real diagnosis.

So I know how important it is to get an early diagnosis. Only then do you have the chance of receiving optimal treatment that prevents lasting physical damage that again influences areas like your work chances and your lifelong quality of life. This year's topic 'Don't Delay, Connect Today: Early diagnosis and access to care in rheumatic and musculoskeletal diseases — the ideal world and the reality' helps demonstrate this so well.

It was great to read this year's Edgar Stene Prize's personal stories that cover this topic exactly. Stefanie Hulst's winning essay reveals impressively how far away reality is from what we patients would like to have, and what should be possible nowadays."

### 2. Marios Kouloumas, EULAR Vice President, representing PARE

"This year's topic for the Edgar Stene Prize is the cornerstone of the effective management of RMDs.

Even though there is no cure for RMDs, many effective treatments are available today that can stop the disease, prevent joint damage and other symptoms, and lead the patient to a remission. Also, there are many diagnostic tools to detect RMDs at a very early stage so that treatment can be initiated immediately.

Through their personal stories, people with RMDs across Europe testify to the importance of early diagnosis and access to care to reduce the impact of the disease and to improve their quality of life."

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

"I am delighted to lead the 2017 Edgar Stene Prize Jury. This year's topic 'Don't Delay, Connect Today: Early diagnosis and access to care in rheumatic and musculoskeletal diseases — the ideal world and the reality' is very important.

Hopefully, driving attention towards the importance of early diagnosis of RMDs and access to treatment — and to all the other issues that people with RMDs face — can help all people with RMDs in different countries to have a good quality of life. It also allows people to feel that they are not alone — that many other people around the world deal with similar problems.

I have been an active member of the Russian RMD patient organisation since 2010. In Russia, early diagnosis and access to care for people with RMDs both have certain issues. On average, it takes patients two years to get a diagnosis and epidemiological data suggests that the actual incidence and prevalence of rheumatoid arthritis in Russia is twice as high compared to official statistics. Personally, I got lucky. I got a diagnosis within two months of having my first symptoms and I started biologic treatment a few months after getting diagnosed. This has resulted in having a very good quality of life six years after developing rheumatoid arthritis.

The Edgar Stene Prize encourages people to reflect on their own lives and those of the people around them. This then results in a more conscious attitude towards RMDs, to the lives of people with RMDs and to one's own life. Together, with my fellow jury colleagues, I want to thank everyone who has participated and supported this great EULAR project, and to congratulate all the winners!"

#### 4. Wendy Olsder, Netherlands, Board Member of Youth-R-Well.com and representative of Young PARE

"It has been a great pleasure and honour to be part of this Edgar Stene Prize Jury. I think this year's topic shows that there is still much to improve in our world to achieve early diagnosis and access to care in rheumatic and musculoskeletal diseases (RMDs). I am so grateful to all the people, from so many European countries, that wrote down their personal stories. By writing these stories, we are creating awareness and taking a first step in improving the diagnosis and access to care of RMDs in Europe.

I enjoyed reading all the stories and I hope they will be an inspiration for everyone. It is fantastic to see young people sharing their experiences of living with RMDs. As for myself, I was diagnosed with juvenile arthritis when I was 14 years old. This was too late to save all my joints, which is why I am really happy with the theme this year."

#### 5. Prof. Tadej Arcin, Slovenia, Chair of the EULAR Standing Committee on Paediatric Rheumatology

"It has been my great pleasure and honour to serve as a member of the Edgar Stene Prize Jury. This year's topic is particularly important as it highlights the importance of getting early treatment. Working as a paediatric rheumatologist, I observe patients during the critical transition period into adulthood, when they are especially vulnerable to the possible negative effects of their disease.

Positive information about living with the disease is particularly important for young people in order to develop and enjoy all aspects of their lives. In this respect, real-life success stories from patients with RMDs are precious and can provide enormous inspiration for patients and their families — and physicians.

I really enjoyed being involved in the Edgar Stene Prize Jury. For me, reading the essays was a remarkable experience and very inspiring. All of the essays were very well written and it is extremely hard to highlight only a few of them."

#### 6. 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. The competition highlights the importance of involving patient and public opinion in advancing the treatment and research of RMDs, and promotes co-operation between patients, health professionals and researchers.

Personally, I was overwhelmed by the quality of the essays and deeply inspired by the sheer determination of people despite the hardship experienced on their journey to receive diagnosis and to access specialist health care.

As a rheumatology occupational therapist, researcher and someone living with a rheumatic condition, I am passionate about supporting self-management. The route to successful self-management is through a collaborative relationship

between the person with an RMD and their health care providers — this allows person-centred goals to be achieved through evidence-based interventions.

I hope this year's essays will help you reflect on your own experiences and inspire you to go that extra mile to meet your own goals."

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

"Serving as a member of the Edgar Stene Prize Jury has been a great honour and pleasure. I have been inspired by the stories and the belief in the future.

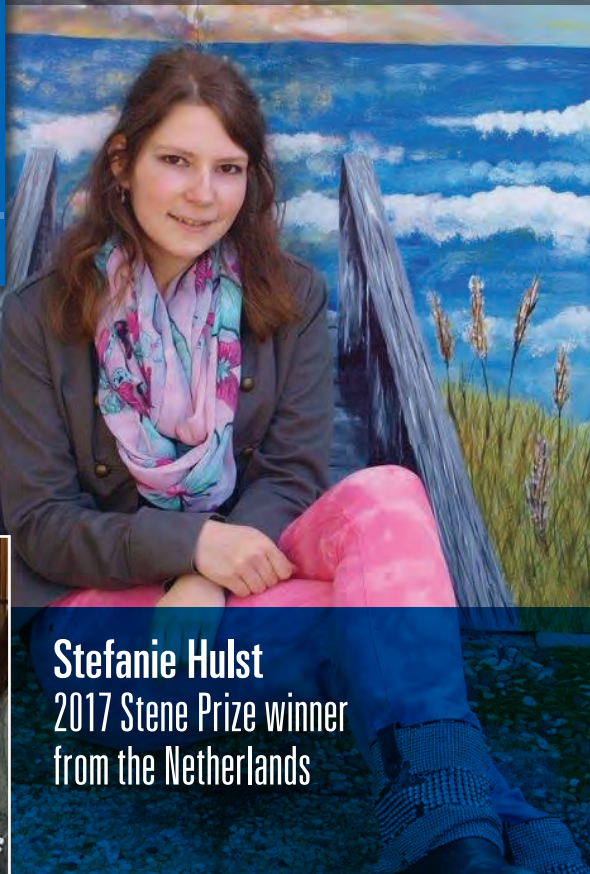
With this year's theme, the authors give the readers a glimpse into their lives, and how we can improve the diagnostics and treatment to close the gap between the reality and the ideal world. I enjoyed reading the essays and hope the stories can change the world for the better.

The stories 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 20 years ago because of my daughter's diagnosis. I have been a board member and leader at different levels of the organisation."



2017  
STENE PRIZE  
WINNER

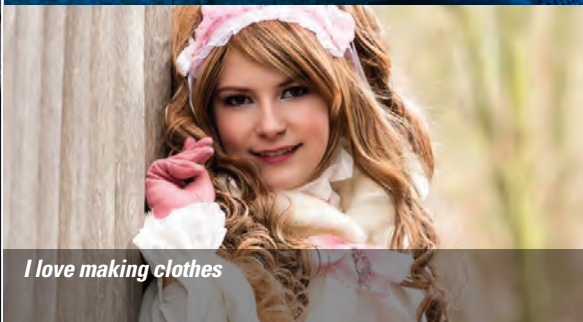
*Here I sit before my painted landscape*



**Stefanie Hulst**  
2017 Stene Prize winner  
from the Netherlands



*Here I am at a puppet fair*



*I love making clothes*

# Diagnosis from the perspective of a child

**I'm 28 years old and have been diagnosed with fibromyalgia. There are plenty of stories about rheumatic and musculoskeletal diseases (RMDs), in particular fibromyalgia, doing the rounds. Opinions differ – the extent to which it limits a person in their everyday life, and what it means to live with it, is a matter of debate. I consider it important that the issue is examined from experience and not so much from a purely scientific point of view because every individual is different and so is every illness.**

By collecting stories from people living with this illness, we can build a more complete picture, which says more than all the articles written by doctors across the world. They only see the issue from a medical perspective, while the person with the illness feels what it does to people.

I hope that my story can contribute to building up this picture and that people will be able to see that RMDs have an enormous impact on people's lives. I hope that, in the future, people can look with respect at the way in which a

person with an RMD keeps going despite all their pain, their limitations and, in some cases, a lack of understanding.

I heard about the Edgar Stene Prize through the National Association of Rheumatism Care in the Netherlands. I see it as a fantastic initiative to put a spotlight on these strong people and their stories, their strength and their perseverance.

**A seven-year-old child with her whole life still ahead of her. Dreaming, perhaps, of becoming a dolphin trainer or veterinarian. A talented dancer, enjoying a carefree lifestyle and a future without limits. Until, one day, she told her mother that her feet and knees are hurting. Her mother, refusing to waste a single minute, took her to the doctor who found nothing wrong and told her: *"Don't worry madam, your daughter is fine."***

The daughter, now in her first year of secondary school, was no longer able to dance. The pain became too much for her, and she had to leave her dancing shoes in the cupboard – only the first of many sacrifices she was to make.

After an entirely normal day at school, she told her mother that her hands were now hurting too. The unbearable



pain in her wrists was making her fingers cramp. She was no longer able to go to school because the overwhelming pain meant she could not write. Following another trip to the hospital, and many tests later, her mother was once again told: *"Don't worry madam, your daughter is fine."*

The girl was kept home more and more often because sometimes she simply could not go to school. Her feet, knees and hands limited her with invisible shackles of pain. She was visited in her home by tutors, telling her she would be unable to obtain her leaving qualification. Forced on despite the pain, fighting against her continuing restrictions, she still had to go to school. Even though she was no longer able to cycle, could no longer use the school stairs and had fallen out of pace with her peers, she passed her final exams with flying colours. Without any help, as the doctors kept saying: *"Don't worry, madam, your daughter is fine."*

### ***"Her new dream was to help people"***

She went on to university as she wanted to make a difference in the world by studying arts therapy. Her new dream for the future was to help people. But from this point onwards, her dreams became a fleeting fog in a darkening world of pain and fatigue. She kept visiting doctors – it was difficult for them to maintain that there was nothing wrong with her as her body told a different story.

Her joints felt as though they were being stabbed. A growing set of pain, fatigue and limitations started to govern her life. However, she kept on going without receiving any help. Because the doctors told her and her mother every time: *"Don't worry madam, your daughter is fine."*

### ***"Despite everything, she got through it all"***

The young woman graduated and was proud to receive her Bachelor's degree. She had to fight a lot, give up a lot, and overcome the depression brought on by the pain. But, despite everything, she got through it all! Despite the lack of understanding from her doctors and the lack of medical assistance, she had fought and won.

Unfortunately, her dream of offering her assistance as a therapist was not to come true. Once again, her plans for the future burst like a bubble – just as they had done many years ago when she was at school. Work became hell. She lost one job after another because of the pain that followed hot on her heels.

Twenty-one years later, the doctors were still saying to her: *"Don't worry madam, you're fine."* Disillusioned by the medical world, she soldiered on with the only drug that the doctors could offer her: *"Learn to live with it."*

Acceptance.

Easy to say by those not suffering from it. They felt no need to fight against the pain and the depression caused by her

loss of mobility and future prospects. By this point, her whole body was consumed by pain and fatigue as a result of the increased number of joints falling victim to her parade of agony. Fitting into society proved an impossible task. At that point, she decided that enough was enough.

A rheumatologist at the local hospital examined her and her medical records for what seemed the 100th time and, after a physical examination, came up with an answer: fibromyalgia. After 20 years – and a seemingly endless fight – she finally had a diagnosis!

### ***"A rheumatologist came up with an answer"***

I was this girl, this woman.

Would my life have been any different if the doctors had listened to me as this rheumatologist had? If they had looked at me, the one who was suffering, rather than the results on their papers? I'm sure of it. They couldn't cure me – there is still no cure for fibromyalgia. But they could at least offer me recognition... Recognition of my suffering and my continuing battle. That could have made a real difference in my darkest days when I felt abandoned and alone – all because the doctors kept telling me: *"There's nothing wrong with you."* Nobody listened to me, and I felt as though nobody was taking me seriously. Twenty years on, doctors acted as though there was nothing wrong with me, as though I was making it all up.

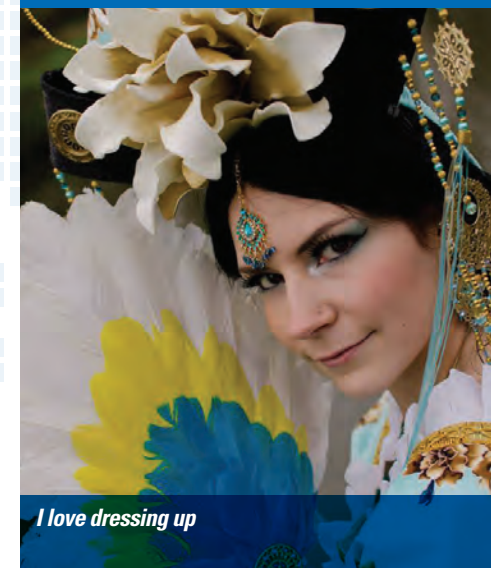
That it was "all in my mind".

My life could have been so different had I not had to fight against both my illness and a lack of understanding from the medical world. It could have been so much help to me if they had said: *"Even though this might not mean much in a medical sense, you should know that I hear you, I see you, I recognise your pain..."*



***I am Stefanie Hulst. I am 28 years of age and have Fibromyalgia***

## **Diagnosis from the perspective of a child Stefanie Hulst**



***I love dressing up***

2017  
STENE PRIZE  
2<sup>nd</sup> place



**Nanna Hanquist Johnsen**  
2017 Stene Prize 2<sup>nd</sup> place  
from Denmark



**Nanna Johnsen**



*I love exercising – this picture shows a run at the event "Copenhagen Half". I found out that training and exercise improves my disease*

# Me and my diagnosis

**I am 24 years old and live in Copenhagen where I study physical education and English at the University of Copenhagen. My ambition is to become a senior high school teacher.**

In my leisure time, I am just like other young people. I love to hang out, have a good laugh and eat cake with my friends... To exercise, run in the sun or swim some lanes... To dance all night at a great party – and to eat pizza and play Yatzy with my boyfriend the day after. I am rather adventurous and travel as often as the State Education Fund grant allows me to. These days some of my spare time is also used at hospitals, taking blood tests etc. These are things I do not love but, well, it needs to be done. Tough luck.

I read about the Edgar Stene Prize on Facebook and immediately thought it was a good way for me to work with my feelings and thoughts. My own words gave me the time to think and a belief that everything will be all right.

**"There's certainly no doubt that you have rheumatoid arthritis." Silence. The words hit me hard. A hard slap to the face. A bludgeoning blow landing right on the spot where it causes the most pain. I look uncomprehendingly at the consultant. I try to say something but the sound has completely disappeared from my lips.**

This is a normal Friday in my life. I've been referred by my GP with suspected reactive arthritis – and I just thought this consultation at the hospital would be 10 minutes and give the reassuring information that I would probably get better. My joints, which had been swollen and painful for the past six months, would soon be better. Back to normal. That's exactly what the consultant would say. Then I'd cycle to a university lecture. Continue my normal life. In my world. A normal Friday. Twenty-four-years-old, fit and

healthy, studying sport, a non-smoker. Why would disease affect someone like me?

***"I'm knocked out by the shock"***

I sit in silence. Uncomprehending. The consultant starts his steady, patient explanation of my diagnosis but I'm not listening. I'm still knocked out by the shock and am trying to focus. The room is made hazy by the tears which are slowly filling my eyes. I dry away the tears in frustration. Breathe. The consultant halts his torrent of speech and gives me a determined look of understanding: "You mustn't cry, Nanna. We're going to get you fixed."

This is how the story about me and my gout started. A diagnosis which, following a three-month investigation, proved to be mixed connective tissue disease. A disease which I had never heard of before, but whose symptoms were a perfect match with mine. Swollen fingers. Excessive tiredness. Body pains. These have been the most difficult months of my, relatively, short life so far. Hospital appointments several times a week to clarify blood



tests, urine tests, lung function test, X-rays, an ultrasound of my heart and many more things. A diagnosis was what they were after. Everything was examined in depth.

More blood tests. Another trip to the consultant. While the doctors endeavoured to arrive at the right diagnosis and treatment, I struggled with acceptance and self-confidence.

My experience of my diagnosis is not far from the ideal world. This is mainly because of my previous association with the rheumatology department. Right from the first day, I was dealt with by unbelievably able and ambitious personnel who hoped things would go well for us patients. I'm unbelievably grateful and humble, given the huge effort the health team make.

## ***"No two people are the same"***

When I didn't understand the doctor's Latin words and jargon concerning the preparations, I was always able to pop in to see the nurse and have a chat, a hug – or a shot of adrenocortical hormone for that matter. Both things gave me a feeling of improvement.

In the real world, diseases can play tricks on even the most capable doctor. Irrespective of how hard you work, you have to accept that no two people are the same and all diagnoses are different. And I was no exception. However, I do wish that I hadn't been confronted with three different

diagnoses on the way to establishing the final one of mixed connective tissue disease. It would have saved me many worries and angry outbursts – and numerous hours of research on "netdoktor".

When a person is faced with a crisis, we go through various phases of grief, anger, denial, working through and acceptance. I went through this phase three times. Each time I was equally distraught about what the new diagnosis would involve for me and my future. For my world. After all the consultants had examined me and the final diagnosis was established, I was in no doubt that it was the right diagnosis. Believe it or not, it was a huge relief.

In the ideal world, the diagnosis is established the first time you go to the hospital so you can work your way through the process as quickly as possible – and come out the other side stronger and process the information. But that's Utopia.

However, aside from this wishful thinking, my diagnosis is incredibly close to what you could wish for in the ideal world. It was a secure and pleasant process during which I was always able to contact the rheumatology department if I had any questions, or needed guidance and information, injections and pills, cream and tissues.

I've just started my medicine. I'll be glad if it works. I've got over the blow I

received on that Friday morning at Frederiksberg Hospital. I want to do everything I can to get on top of it. And, fortunately, I'm surrounded by the best network of friends and family in the world who will support me through the process.

## ***"A diagnosis can feel like a slap in the face"***

I thought my diagnosis was the end of my world. But I became wiser and have learned an awful lot during this process. A diagnosis can feel like a slap in the face; the world's worst knockout. But I've got up again and, this time, my self-defence is up.

A small number of people with my diagnosis do feel that the disease will disappear. That's not what I think. In any case, I have no intention of giving up without a fight.



***My sister and me. We are very close and have always been***

## **Me and my diagnosis** **Nanna Hanquist Johnsen**



***My sister and me having fun with our friends***



2017  
STENE PRIZE  
3<sup>rd</sup> place

*A journey makes you forget all your troubles*



**Eszter Rozán**  
2017 Stene Prize 3<sup>rd</sup> place  
from Hungary

*Eszter Rozán*



*I do not care about the disease – I keep on studying*

*In remission: receiving my prize*



# The uninvited guest

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

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

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

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

reminded me of his presence again when I went swimming.

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

He just shrugged and stayed. I thought the best strategy was to get on with my life and pretend that he didn't exist... Perhaps he would disappear. I think his persistence merits respect because he didn't leave me for a minute. Instead, he insisted on becoming a part of my life and staying with me forever. Some relationships are constructive and change our lives for the better, filling us with energy in everyday life. This relationship was definitely not of this kind. From the very first moment, he was bent on destroying me physically and mentally. He attacked on several fronts. He made it difficult to move, he caused me pain wherever he could – at first only in small joints, gradually moving on to more and more body parts – and he also started to impair my mood. After a while, I realised that this was no laughing matter and I must seek help to get rid of him. Before taking decisive steps, I made a last attempt.

"Will you go away, at last?"

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

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

## ***"We would see who would win this fight"***

When I visited the first specialist, he started his childish games again – he hid, pretending that everything was fine. I

understood his strategy: if he wasn't discovered, we wouldn't fight him, and he could continue his destructive work beneath the surface. However, there was evidence of his presence, albeit not conclusive – just a factor indicating his presence. My first specialist doctor was, indeed, tricked by him. While the doctor admitted that my new "friend" visited me, he thought that this would be just a fleeting acquaintance, and he would go away when he got bored. Of course, we could help out him with some innocuous drugs and ointments, however, he would surely go away – that's what the specialist said, confidently.

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

## ***"He knew my 'friend' was not well-meaning"***

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

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

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

One day, my rheumatologist showed me a leaflet. He told me I had an opportunity to try biologic therapy as part of a medical experiment. He also told me that we were still in time and, usually, even the

most stubborn of visitors backed away from this. Although a few unusually persistent individuals held on to their hosts at all cost, in most cases this treatment worked.

## ***"One hour after the first injection the stiffness was gone"***

I did not hesitate for a moment as my guest had become unbearable by this time. I could not open my front door without help and brushing my teeth was torture. I could not wait to get through the preparation phase. Then I received my first injection. I had to learn how to inject myself and, while that wasn't very difficult, I had some difficulty preparing the solution myself. I soon got the hang of it. I felt relief even after the first dose. One hour after the first injection the stiffness was gone. My visitor was wailing. Improvement was gradual and my partner did not want to bid me farewell, but he had no choice.

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



*When moving was still difficult*

## **The uninvited guest** **Eszter Rozán**



*On the road to recovery*

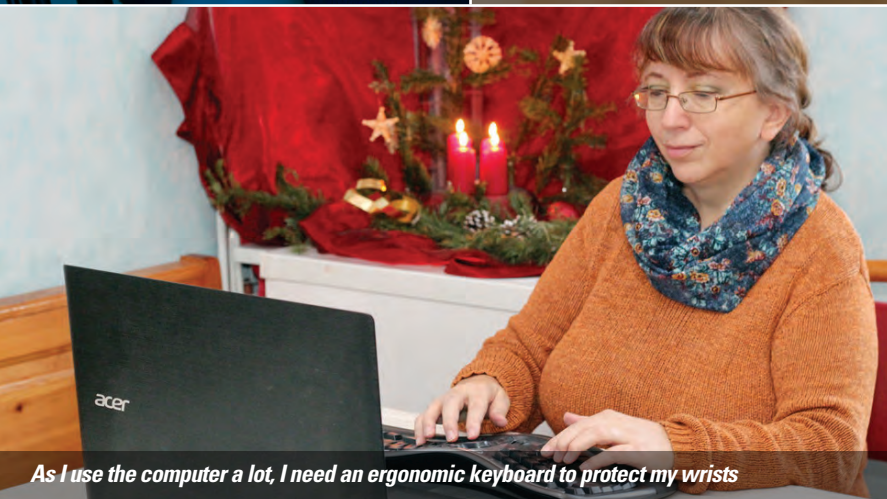




**Hanna Zauner**  
Austria



*Wearing cute, high-heeled shoes has been a thing of the past for the last 15 years – I can only wear specially-designed orthopaedic shoes*



*As I use the computer a lot, I need an ergonomic keyboard to protect my wrists*

# Ideals versus reality: My personal story

**I am 55 years old and have had rheumatoid arthritis for over 20 years. I have been married for 37 years and have six children. After our youngest child turned 12, I started looking for work again. For months, I looked for work that I would be able to manage despite my arthritis, but it was to no avail.**

Now I'm a housewife. I never get bored – I love cooking, photography, playing guitar and writing. I also spend a lot of my time volunteering for two different organisations.

I live in an Austrian town with 200,000 inhabitants and excellent healthcare provisions. The rheumatology department at the local hospital is run by a renowned specialist who has been personally committed, using her specialist knowledge, to taking care of me.

I found out about the Edgar Stene Prize thanks to a flyer on the notice board in the rheumatology department.

So far, I've been impressed. I've actually found somebody who wants to hear my story! Aside from that, I really like to write, so that was my second incentive to take part.

Also, I would be lying if I said the idea of winning a prize didn't motivate me even more!

**"Take a look at this. Is my finger swollen?"**

**My sister had come to visit me. Before she had a chance to get her foot through the door, I thrust my hand in front of her for inspection.**

We examined the suspicious looking finger closely together.

"Yes, I think it is... Or maybe not?"

We stood considering the issue for some time, until finally we concluded that it was impossible to tell whether the finger was swollen or not.

Going to see a doctor didn't even cross my mind. I wasn't in pain and the swelling of my finger wasn't a cause for concern. I wasn't even sure if my finger was swollen. That was February 1993.

**"Perhaps the shoes were a little tight?"**

Three months later, in May, I was experiencing pain in a completely different place. I had received a new



pair of shoes as a gift from my neighbour, so I decided to put them on to go for a little walk. Perhaps the shoes were a little too tight? They pressed against my heels as I walked, until I couldn't take the pain any more. I took off the shoes and walked home in my bare feet.

From that day on, I couldn't wear shoes without experiencing intense pain. I mostly walked around barefoot. Finally, I dug a pair of old walking shoes out of their box, which made the pain just about bearable when I walked in them.

I still didn't get that doctor's appointment. Clearly, I thought, I had pulled a tendon, and would be right as rain if I just rested. As summer came to an end, my feet still weren't better. In fact, aside from being painful, they had also become extremely swollen.

I decided to see a doctor. He had a few ideas about what could be causing the problem and an X-ray would clear things up. In the meantime, however, I had fallen pregnant and would need to wait until after the birth. I did well during my pregnancy, but that soon changed once my son was born in April 1994. I couldn't properly extend my foot while walking. I could only go down stairs by walking on the outer edges of my feet. I think I was wearing leather soles the day I slipped and fell down the stairs.

### ***"I couldn't ignore the pain any more"***

Finally, the day came when I was due to go back to the doctor. I couldn't ignore the pain any more. My GP referred me to an orthopaedic specialist. He was a specialist in many things but, apparently, rheumatic disease wasn't one of them. He decided I didn't need an X-ray and felt that blood tests would be completely unnecessary. Instead he simply pressed down somewhere on my foot and said: "This must hurt". He ignored my tentative objections and concluded that it was soft tissue rheumatic disease.

The tablets helped... For three whole days. Then the pain became so unbearable that I went to get a second opinion. This time I had to pay for the injections to help with the pain as they weren't covered by my health insurance. The injections helped, too... For three whole days.

When I called the orthopaedic specialist for an emergency appointment, I was greeted by a message telling me he was on holiday. As it turned out, this was a lucky chance for me – I wanted to ask my own doctor for advice.

"Soft tissue rheumatic disease is curable!" the doctor assured me. "A few days of infusion treatment will sort it out!" A friend of mine took care of the baby and I went to the hospital.

Before the doctors began the infusion treatment for soft tissue arthritis, they wanted to confirm the diagnosis I had been given. It took several days and a number of examinations until one doctor declared triumphantly: "Now we know where your pain is coming from! It's rheumatoid arthritis!"

By the time I was diagnosed, the rheumatoid arthritis had caused so much damage that you could even see it on an X-ray!

### ***"There were times when the pain was unbearable"***

During those first 15 months between the appearance of the first swellings and the diagnosis, I didn't experience any fear or anxiety. Things only took a turn for the worst after the diagnosis. Despite all the medication, there were times when the pain was so unbearable that I just sat crying on the sofa, longing for death.

Today, the therapy is very effective and I feel pretty good. Perhaps one or two of my operations wouldn't have been necessary had I been diagnosed earlier. But I refuse to sit around bemoaning my fate.

Besides, something good has come from all of this: a woman who is Chair of the board of one of the organisations I am involved with started experiencing occasional pain in her hands. Nothing

major, but enough to be a nuisance. I sent her straight to the doctor, told her not to put it off for another second, and to tell them she thought she might have rheumatoid arthritis. It's been a few years now since she was diagnosed but, with good medication, she barely has any problems at all.

By the time I had reached the same stage with my own arthritis, I had already had my first operation – a synovectomy.

Early diagnosis can make all the difference!



***I'm very thankful for my wrist supports, which enable me to do housework without any pain***

## **Ideals versus reality: My personal story Hanna Zauner**



***I couldn't play for months when my rheumatoid arthritis really started to flare up, but now my fingers are working again***



**Karen Rogghé**  
Belgium Flanders



*During a trip to Turkey*



*Enjoying horse riding on my holidays*



*Nice little walk with my boyfriend, recently my fiancé, and my parents-in-law's dog*

# My story: A long road to diagnosis

**I am a 28-year-old nurse working in a hospital in Bruges. I love my job because it allows me to help people – something which gives me enormous satisfaction.**

I also live in Bruges, in an apartment with my fiancé. We have a cat to keep us company during the more difficult times. I'm still young and I try to cope as well as I can with my illness, but I know all too well that it comes with its ups and downs. I focus on the more positive aspects – the things I can still do – and I enjoy life.

I found information about the Edgar Stene Prize on the website of the Flemish Spondyloarthritis Association. I was very keen to take part in this competition because my path towards diagnosis was long. I wanted to tell my story so that doctors make a diagnosis more quickly and patients can be treated faster without having to experience the long waiting times that I did. I want to use my story to let other patients know that they are not alone in their long search for a proper diagnosis.

**After I completed my nursing studies, I started working in the surgical department at a hospital. I wanted to work on my physical condition in my free time, so I joined the local gym. I worked out intensively but, after two months, I suddenly started to experience pain in my lower back which radiated to my left hip. I put it down to overdoing things. I stopped going to the gym, but the pain never fully abated and kept coming back.**

After six months of persistent pain, I made an appointment with a sports physician at the hospital where I work. He suggested taking an X-ray of my pelvis and an echocardiogram of my left hip area. There was nothing amiss with the X-rays, and the results of the echo were inconclusive. The doctor said that

my hip and lower back muscles were probably too weak, and sent me home with a note for the physiotherapist who was to give me exercises to improve the muscles. If there was no improvement after six weeks, I was to make a new appointment.

As I did not notice any improvement, I duly made an appointment. In fact, the pain radiated to my calf. During my examination, nothing was found that could explain my pain symptoms. The doctor suggested a hernia, so I agreed to magnetic resonance imaging (MRI) and computerised tomography (CT) scans of my lower back. I had the scans a month later and, the month following that, I went back to the doctor.

***“Neither scan yielded a diagnosis”***

Once again, neither scan yielded a diagnosis. The doctor told me that the symptoms might be attributed to hyperflexibility and advised me to continue my physiotherapy in combination with pain management. The conclusion, therefore, was that the flexibility of my joints was the cause of my pain.



I doubted this diagnosis because the pain refused to abate, so I made an appointment with a professor of sports medicine in Ghent University Hospital. I told my story all over again but, by this time, I had developed pain in my right hip. Nothing was found during the clinical examination. The professor suspected that the positioning of my feet was causing the problems so ordered gait analysis to be carried out. This test showed that my right foot was positioned slightly incorrectly, so it was recommended I use insoles. However, this did not help so I made another appointment with the professor.

### ***"The pain became more severe"***

The pain became more severe, so he decided to carry out a physical examination. Three examinations failed to improve the situation, so he suggested another MRI of my lower back, combined with an MRI of the sacroiliac joints. This latter examination showed sacroiliitis to the left-hand side, indicating ankylosing spondylitis. I then underwent a blood test and a colonoscopy to rule out Crohn's disease.

During this period, I was faced with considerable uncertainty and fear because, as a nurse, I knew what I would be facing if Crohn's disease was found. Thankfully, I received support from my family and boyfriend and I knew I wouldn't be facing Crohn's

disease on my own. The colonoscopy showed that I did not have this condition. My blood test results, however, showed that I was HLA-B27 positive, but the professor was still unable to confirm whether I had ankylosing spondylitis.

Once again, I was referred to a doctor at another hospital. The same tests were requested, but I refused. Things had been going on in this way for a year and a half, and I still had no clear conclusion as to what exactly was wrong with me. In the meantime, I had been taking pain relieving and anti-inflammatory medication, which reduced the pain to a tolerable level. Six weeks later, the symptoms began to increase once more. I found information on the illness online and stories shared by patients showed that they were being treated by a rheumatologist.

### ***"I was relieved that the diagnosis had been made"***

On my own initiative, I made an appointment with a rheumatologist and told my story once more. The rheumatologist made it clear that a diagnosis of ankylosing spondylitis could be made. Even though I suspected I had this disease, the news still came as a shock. In some ways, I was relieved that the diagnosis had been made and that I could start treatment. I started on a biologic drug and my symptoms simply melted away. I could get on with my life.

After a few months, however, the pain started again and this was attributed to a bilateral hip impingement. I underwent an operation for this earlier this year and I am currently still recovering.

### ***"There's still plenty I can do despite my illness"***

After two years of uncertainty and pain, I can finally start the treatment process. I have to confess that I never expected the illness to have such an impact on my life. At work, I've transferred from the care unit to a less strenuous department to keep my symptoms as well under control as possible.

The illness has had a huge impact on my personal life: I can't run my own household and need help to keep things going. Luckily, my boyfriend helps me out and takes on the heavier household chores. If I've had a bad day, he takes on as much of the work as possible, and continues to support me unconditionally. We've found a balance in terms of what chores I can perform and what I'm no longer able to do.

I am fully aware that I need to listen to my body, and that I will have to keep doing so throughout my life. I hold on to the thought that there's still plenty I can do despite my illness — although I sometimes feel a sense of longing when I think of all the things I used to be able to do but which the pain now makes impossible. I exercise as much

as I can within the limitations of my pain, but I have to rest often. The most important thing is to be able to live with the pain.

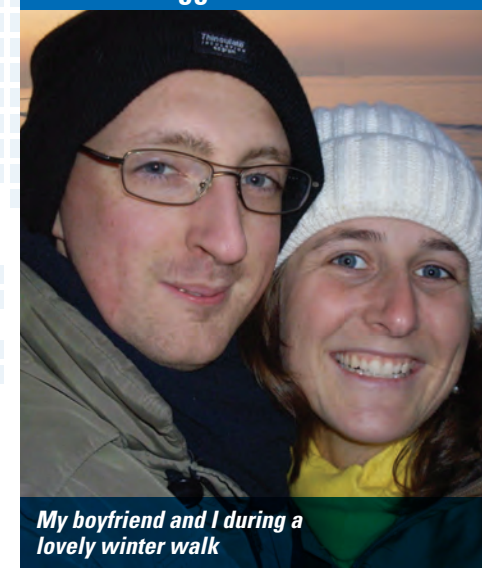
I am certain that an earlier diagnosis would have made a difference in my case — my pain would never have been as severe, and the illness would have been under control more quickly. An early diagnosis would also have ensured that medical expenses didn't get too high. I bought all kinds of painkillers and support soles that had no effect whatsoever. The various visits to the doctor, the examinations and scans also had a significant financial impact. Thankfully, we have a welfare system in Belgium that makes the treatment costs bearable.

In my case, the ideal situation would be for the doctor to have diagnosed hyperflexibility, referred me to a specialist doctor and for the examinations not to have required three repetitions before the diagnosis was made.



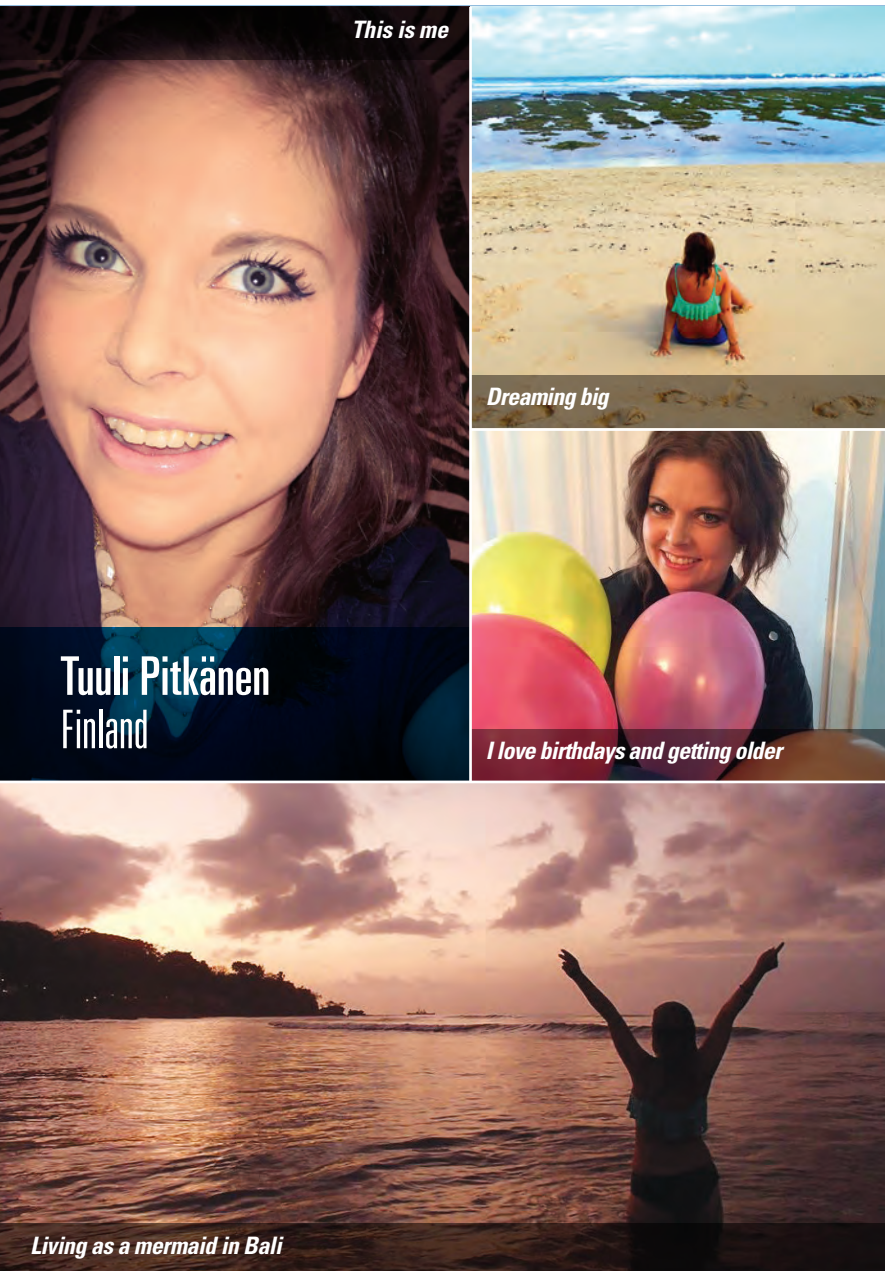
*With my cat when she was still little. She keeps me company when I have a bad period*

## **My story: A long road to diagnosis Karen Rogghé**



*My boyfriend and I during a lovely winter walk*





**Tuuli Pitkänen**  
Finland

## Dear Diary

**I am a 32-year-old woman from Siilinjärvi in Finland. I now live in Helsinki and study literature and film studies, but my former occupation was as a biomedical laboratory scientist. Three years ago, I had to give up work due to my rheumatic disease. Ironically, my disease was what encouraged me to study and work in healthcare in the first place. When I was at a crossroads, I went for my other passion: stories – both in literature and in films.**

I decided to participate in this competition as therapy for myself – it was a way to deal things and events that happened years ago, but which still affect my daily life and decisions.

At the time I got sick, I was a 16-year-old schoolgirl, scared and confused. I had my family to back me up – my mom, dad, big brother and big sister. And I had good friends who still walk beside me after all these years. I rarely tell people about my

disease, but these ones have been there for me from the start.

Laughter is one of the most important things when it comes to surviving with a chronic disease and pain. This disease has taught me a lot, possibly more than I even know. It has also taught me that, if there is nothing more to hang on to, you can always just laugh. It has a miraculous power.

**06.05.2001**

I am changing to become a mermaid. I am forced to as I am growing scales. The dreams of my childhood are becoming a reality. Growing pains, as that's what they are likely to be; a tail is growing in place of my feet. I always thought that you are born to be a mermaid but perhaps I have a genetic defect making me change only now I am a teenager. However, I have always loved water and swimming. My mother used to say: "That's where she lives – in the lake." However, I wouldn't have believed that the transformation would be this painful.

The colour of the white scales replacing my skin has gradually become darker. At times the scales bleed. They itch. I try not to scratch as I am afraid that the human skin will grow back and then the tail will not grow. What kind of hands do mermaids have? My own fingers have changed and become pure white, at times they are bluish: they are ice-cold. My feet are painful and ache, particularly in the mornings. I think that is because, in the

mornings, the force of the lake is at its maximum energy level and it is calling me into its kingdom. Why doesn't the tail grow faster?

**16.02.2002**

I have now been waiting for the transformation for almost two years. The scales have increased and changed to brown. They feel tight; it feels strange. Don't mermaids gleam beautifully in blue or green? Not brown! There is no sign yet of the tail emerging, even though the growing pains become stronger every passing day. I watch the lake every day hoping to see Neptune waiting for me. I am sad, desperate, disappointed. My mind is full of doubts. I keep on spraying water on my feet; it cools them down and eases the hot aching.

**28.02.2002**

This morning I can't walk anymore. I wake up in my own bed, on land. I wonder whether I should crawl to the water by the shore — perhaps I have gills which have replaced my ability to walk and I can breathe under the water? My father carries me to his car and takes me to hospital. What if my big secret is now revealed to everybody? I would rather dive deep down to the bowels of the lake than let anybody undertake trials and tests. The White Coats just stare at me. Gathered into groups, they keep on jabbing and

poking me, murmuring among themselves. They take a piece of my scales to study. I am scared.

**12.04.2002**

I have already been absent from school for more than a month. I have been given crutches; I have not grown any gills and, yet, I have not got back my ability to walk. Tomorrow I have to meet the White Coats again; they will reveal what has been found in the examinations. I don't know whether any mermaids have been examined before. Do they suspect? Do they know what to look for? I have lied to them all, saying that I fell over and hurt my feet. I cannot tell the truth as I don't know it myself. Perhaps I will know tomorrow.

**13.04.2002**

The White Coats told me the truth today. Scleroderma. A mystical, strange word. I am not growing any scales after all — the skin of a human just somehow changes to become weird, hard, inflexible, tight. No gills have grown, even though something is going on in my lungs. I cannot breathe the way I used to — it feels as if there is something extra in my throat. Eating is difficult; it feels as everything is somehow stuck.

My hands don't function as they should. I have my A-level examinations in the autumn; I don't

know how I will manage them. Recently I have fainted several times and in all kind of places. I think that it's because I wish to escape from this world to somewhere else — to the lake kingdom. However, my dreams haven't come true. They have been replaced with a weird word which I don't feel is mine.

**10.10.2016**

Last night I read my old diaries. The entries in them were made quite a long time ago — over a decade ago. That strange word does not feel so weird anymore, even though it's not quite mine either. However, it is travelling with me. That word has restricted, suppressed and threatened me. It has been opposed and been rebelled against, taken me from a lunatic asylum to gratitude, taken it all and, at times, even given something back — at times something new and, at times, something old.

I have still been living in the lake and spraying water on my feet, still wishing the tail to grow. During the 15 years, this human carcass has aged faster than time or the mind. It has been difficult to readjust.

I still don't like the White Coats. Anyway, they wouldn't have been able to help me any better; they didn't know about mermaids any more than about that strange word. They still just stare, gather themselves into groups, keep

on stabbing and jabbing me, touching and murmuring to each other. At times, I murmur something back to them but we don't seem to understand each other's language. Not many here understand the language of mermaids.

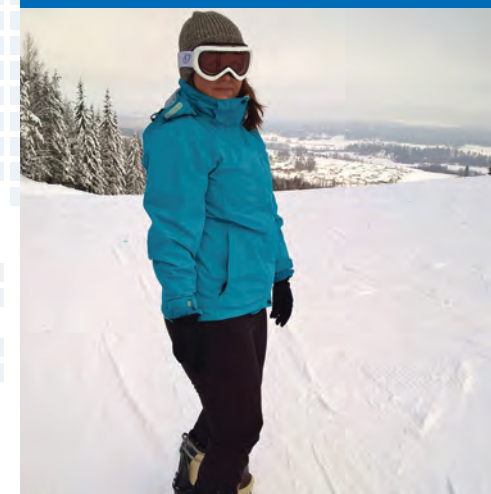
Today I walked again to the shore. I think I saw a splash of a tail on the water's surface.

*Hardened Mermaid*



*Fascinated to learn and see other cultures*

**Dear Diary**  
**Tuuli Pitkänen**



*On good days I still can do some of my childhood hobbies*





Our scleroderma group participating in the run MOVER on 16 Outubro 2016



Some of my students

# Living my life beyond systemic sclerosis

I am 49 years old and originally from Luanda in Angola. I am divorced and now live with my 21-year-old son in Almada, Portugal. I have limited systemic sclerosis. I practise Pilates and yoga, and I have adopted a macrobiotic diet. I love reading, writing, photography and arts in general.

I have recently discovered a new passion for teaching and I give private classes in mathematics, physics, chemistry and biology. I like the idea of helping to "shape people". I heard about the Edgar Stene Prize through the scleroderma group of the Portuguese League Against Rheumatic Diseases, which I recently joined. I support similar groups and associations from around the world.

I think that, even though there may be few of us, a lot can be done with a little. And, through our actions, we can change the world – at least the part of the world that we manage to touch. That is why I was moved to participate by making my contribution, and expressing my outlook, experience and expectations.

I had a life of excess, living on the edge both emotionally and professionally. I am a happy woman because I have lived life "as I very well please". Yet, all happiness brings us moments of deep unhappiness. All this intensity hid signs that something was not right. But I considered it normal, at least for me, reasoning that it could simply be a manufacturing defect. But what was normal became abnormal, and the need to understand what was wrong led to the search for medical attention.

After a few years of research and all kinds of tests, the diagnosis started to take shape as the numerous effects emerged at an increasingly rapid pace... Until the day I received the diagnosis

that made me stop for a moment: pulmonary embolism (PE) which then resulted in systemic sclerosis (SSc). The SSc was not yet at the worst stage – as if that was supposed to comfort me.

For a split second, my world stopped. I had to think, to locate where this SSc was and where I was! "Whose choice was this? Was it for me or the SSc?"

Then I made a decision: "I am going to turn things around. That's that!"

**"For a split second, my world stopped"**

It was time to research, understand, accept and take measures to fill the gaps that had brought me to this encounter. I was trapped into living with this Woman! Yes, it is a Woman because it is independent and it has authority.

"But does it really have these qualities?" I wondered once again. And I reflected on not wanting to be ill but knowing that I have a disease. Here lies the difference in ownership. "Is it me who has the disease or is it the disease that has me?!"



At times, we briefly question what it is that brought us to each moment of our life, and we understand that our choices end up meeting our needs because we always have an alternative. For me, the hardest part was recognising that I have limits. I am used to continuously going beyond them, but my body forced me to stop in order to overcome and survive my SSc.

So, I felt compelled to reshape my everyday life – find alternatives that would allow me to carry out my duties and be happy, but which would also respect my body's limits which I discovered existed. I also decided to reclaim ownership over this same body which I accepted as my own. Surprisingly, I realised that it is possible! I set aside time for myself – to properly treat myself without giving up carrying out my tasks – and even managing to live my turbulent everyday life. Without chaos there is no order – entropy; and without chaos there is no energy – enthalpy. We only need to learn how to manage this balance.

## ***"I learnt to manage the worst challenge of them all"***

For my physical concessions, I found Pilates and yoga – both of which I tasked with helping me regain control and physical balance. But my body insisted on surrendering. As my stomach weakened each day, I faced yet another challenge for which I found

a solution in a macrobiotic diet. In the enthusiasm to find solutions, I learned to manage the worst challenge of them all: the tiredness of the world. However, I realised that once the rest of things are balanced, the tiredness is also kept under control.

This persistent and never-ending maze, which takes me on a constant search for solutions, together with the research and monitoring of all new scientific findings which can help me understand and get to know my autoimmune disease, has ended up adding value to my life.

I rediscovered in myself a new purpose that I was prepared to enjoy. In light of my understanding of the disease, I felt that I could improve the lives of other people who have this and/or other diseases. This is what inspired me to share my outlook here, based on my reality. I think that we are primarily co-responsible for our disease and, prior to any medical and therapeutic team, it is for each of us to identify every symptom and possibility connected to scientific research. It is our obligation to get involved in the treatment, in the search for a cure. I do not accept chemical therapy which only serves to hide the symptoms associated with the disease. I accept therapy that is necessary and which curbs any existing pathology, new pathology and/or which treats the disease. At the most, I want to "share" part of my body and my life with SSc, without ever giving it all that I am.

I was born free, born to be happy. I was born on African soil, where we are what we want to be... Because being is a state of mind. We are born under the sun, with the wonderful scent of the earth, and we go to bed under the moonlight. I am not handing over my soul and my life to the invisible, which has the misfortune of being unloved, as is the case of this SSc.

## ***"I plan to fulfil my mission"***

I have been fortunate to live in a time of incredible changes. I have seen the birth of the television, mobile phone and internet. I have seen science evolve as miserable decades flew by, rapidly bringing us to the 21st century where miracles are performed by science. That is why I am a woman of faith.

I believe that, very soon, there will be a cure for autoimmune diseases. But I also think that if there is not a change in behaviour, these diseases will persist. As the name suggests, they are autoimmune and, whether we like it or not, we are primarily responsible for what lives inside of us.

I was born free and happy, ready to live an intense life. I intend to die free and even happier because I plan to fulfil my mission and I still believe that I can change the world... At least I managed to bring to the present the soul with which I was born, in spite of such a turbulent trip through time.

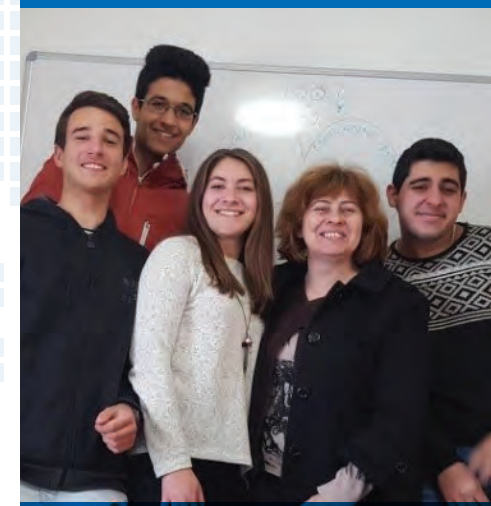
## **Acknowledgements**

I would like to thank the medical team which has accompanied me, starting with Dr. Maria de Lurdes Ferreira from my health centre in Sobreda. In 2005, she referred me to internal medicine for appropriate investigations following an extremely high ANA test result which had not been confirmed by any other possible prospects. From the Hospital Garcia de Orta in Almada, I would like to thank Dr. Tiago Judas from internal medicine for his insistence on carrying out all the tests. He is probably responsible for me being alive, since it was while carrying out some additional tests to rule out unlikely possibilities that the PE was discovered on a lung scintigram in 2014. I would like to thank Dr. Sandra Sousa from rheumatology, and Dr. Melanie Ferreira from internal medicine, who have accompanied me since 2014 and who work as a team, for their dedication to their patients.



*I enjoy my Pilates*

## **Living my life beyond systemic sclerosis Paula Calado**



*Together with my students João, Robin, Raquel and Bruno*



**Lucia Slejšáková**  
Slovakia



*Sightseeing in Kosice is a bonus after a visit to the doctor*

*A Senior Club trip to High Tatras in Spišská Nová Ves is focused on getting in shape*



*Hiking in the High Tatras with children from Klub Kíbič*

# Learning to be strong

**I am 36 years and on a partial disability pension. I have been unemployed for two years, only working occasionally. I volunteer at Klub Kíbič (an NGO for children with juvenile idiopathic arthritis and their parents) and at the Slovak League Against Rheumatism where I am also a Board member.**

I was born, and still live, in Spišská Nová Ves. I am single and live with my mom who is a widow. My interests are reading, creating handmade things, nature, gardening and workshops for children.

I found out about the competition on [www.mojareuma.sk](http://www.mojareuma.sk) (the Slovak League Against Rheumatism website) and from a Facebook group.

I decided to take part to support people with rheumatic and musculoskeletal diseases (RMDs) in their fight with the disease – to encourage them and to inspire them never to give up despite it sometimes being very difficult and challenging.

**I am one of about 100 people around the world born with a rare autoimmune disease called CINCA syndrome. It is genetically caused by a mutation in the first gene and is of rheumatic origin. I will give a short account of what is involved.**

Just a few hours or a few days after a baby is born, very painful and itchy red non-suppurative papules appear all over the body. The papules can take many forms and can appear without a connection to anything else. Fatigue and chills may also occur, and then fever, which progresses into prolonged fevers lasting several days at a time. Swelling, pain, and redness of the limbs and small joints will gradually appear, with the large joints being affected later. Extremely severe headaches, which occur unpredictably, are a further complication. The headache attack comes in a “wave”, flooding the whole area of the head with pain. The muscular part of the body along the spine is affected by a strong and painful spasm, locking the body in the foetal position for several seconds. The wave goes into remission, but can recur

with full force. It is often accompanied by vomiting and diarrhoea, can last 24 hours and then fade away the next day. Severe inflammation of the body and severe anaemia may also appear.

The disease attacks the central nervous system and the senses, gradually causing problems with eyesight and hearing. Half the people with my disease will not live to adulthood, mainly due to related diseases of the heart, kidneys, lungs and stomach. Half of the patients with this disease also have a certain degree of learning disability.

For me, all these symptoms led to an endless series of hospitalisation in several hospitals in the former Czechoslovakia. I was treated most frequently in Prague. I have mixed memories of fearing new people, the foreign language, the isolation from my parents and the feeling of terrible loneliness. The treatment wasn't really treatment at all and arriving at a diagnosis was rather a hit-and-miss process involving guesswork – none of the doctors knew what was wrong with me. I was young and I had to cope with severe psychological stress, pain and the “why me?” question.

Despite my symptoms, I attended compulsory primary school without any restriction, although I was excused from physical education. If my health



deteriorated, they would send me home. Frequent hospitalisation meant I was often absent from school and I had problems catching up with the curriculum. However, the biggest problem occurred after I began attending grammar school. In the first year, I developed ischemia of the lower limbs during a severe tonsil infection. My legs from the knees down became terribly cold and I experienced severe pain due to thrombosis. I could not feel the lower part of my purple and blue-coloured legs and there was a real risk of having both legs amputated above the knees. At the very last minute, my legs recovered and I went back to school after two months and became the “black sheep of the class” because my study results were obviously poor.

## “A high level of IQ”

I attended all the mandatory medical examinations with a psychologist and a psychiatrist to determine whether there was a valid reason for excluding me from school. The examinations, however, showed a high level of IQ with all manifestations of an introverted and melancholic personality. I stayed at the school and, by the last year, I was among the best students. In the end, my intellect wasn't as poor as some of the teachers had thought. Over time, and with my own strength, I successfully graduated from three universities. I hold degrees in environmental ecology, teaching and social work in healthcare.

I'm on a partial disability pension. I need to work at my own pace, but I manage to achieve what I plan to do. My illness did what it wanted with me. Several different

treatments were applied to combat the disease. I was subjected to hundreds of injections and infusions. I endured many painful tests. Even so, over 25 years the doctors struggled to reverse the symptoms of the disease. However, one day my life was turned around 180 degrees. After a blood test was sent to Paris for DNA analysis – and after a wait for the results lasting three years – my disease was finally identified.

Less than two years later came the biggest turning point in my anguished life – the opportunity to try a new biologic medicine which could bring a positive change. The doctors showed me the results of the clinical drug trials and gave me the freedom to decide. By now, it felt like I was only a caricature of a person. Feelings of worthlessness, helplessness and the humiliation of having to be dependent and reliant on the help of others were literally killing me. I had nothing to lose. I agreed.

The drug worked. My rash disappeared within 24 hours of the first injection. I had to apply the second injection under the supervision of doctors. The rashes in the coming days and weeks did not appear. I could not believe my eyes. Never in my life had I stood so often in front of a mirror. It was a huge mental relief. The biologic treatment gradually took effect elsewhere, but it still took nine months to achieve remission. My drug is not without side effects, but I use natural ways to keep them at bay. I don't take any other medication. This is, in part, thanks to my efforts because I've been watching my body for years – I know my body and its reactions to its surroundings. I'm a

vegetarian, a non-drinker and a non-smoker. I use alternative medicine, namely acupuncture, inhalation and medicinal herbs.

The medicine, however, does not have an effect on the headaches and sensory disturbances. Although my sight has stabilised, I'm short-sighted – although I wear glasses only when driving. My hearing is bad enough – I've been diagnosed with a moderate to severe form of bilateral hearing loss which is accompanied by a humming, whistling and buzzing in the head. The noises vary in intensity and cannot be muted or cancelled. Despite having hearing aids, these noises make it impossible for me to understand a normal conversation. They cause problems in my communication and orientation, and cause many stressful situations.

In an ideal world, my blood would have been sent to Paris for DNA analysis at least 20 years ago. I would not have had to wait for the results for so long. In an ideal world, the biologic treatment would have been available from the very first appearance of the disease, before the symptoms fully developed. This would be a miracle and people with CINCA syndrome scattered around the world would not have to suffer as long and so terribly.

## “None of us are just a diagnosis”

I have written about my own real microcosm, about the helplessness of doctors and their best intentions to help me even though they didn't know exactly how. The disease took away my carefree childhood and brought an early adulthood.

I had to always be rational, brave, suffer silently, stand out of the way and be a “guinea pig” without protesting. I did not experience exciting adventures as a child. I have not experienced first love, marriage or children. I did not choose this disease, it chose me. While in cruel, long-term pain and with an inability to take care of my basic needs, I often begged God to take my life. He did not.

However, this disease has taught me to be a strong person and to better understand the needs of other people. It has given me the gift of patience and the understanding that a good period can change for the worse and then become better again. It has taught me to appreciate the unconditional love of my wonderful parents. Their support and assistance would not let me fall to the very bottom. It has taught me that there is no need to rush things, to own the material world, or to prove anything to anyone. It has taught me to rejoice in the little things – to realise the beauty and uniqueness of all living beings and nature, and to love and understand people as they are.

Like me, you also have the right to live life to its fullest instead of just being passive and resigned to life. None of us are just a diagnosis. Each of us needs a helping hand sometimes. Let us accept this hand, but let us offer it as well. Let us be there for one another, for this world, for all people and for nature. Let us take care of them with love. Love really is the driving force in this world. This is how I, Lucia from Slovakia, see it. Who, with her body, is fighting this rare disease – mostly winning over it and sometimes losing. Because this is just how life works.



During the camp for children organised by Klub Klbik

## Learning to be strong Lucia Slejšáková



With one of my university diplomas





Vanesa Yuste Aguado  
Spain



My son Hugo, my dad and I at a race organised by the Reina Cristina hospital in Parla to support the public health system



In EULAR, Madrid, 2013



The four of us with our adopted dogs in the countryside collecting pine cones

# Ankylosing spondylitis: My personal story

**I am 41 years old and currently work as an administrative assistant in an office. I like working but it is very difficult for someone with ankylosing spondylitis (AS) to sit in the same position for a long time, especially in front of a computer which is exhausting for the cervical and lumbar region.**

I was born in Madrid and grew up between Madrid, Guadalajara and Ávila. I love anything to do with nature and animals, and I'm happiest when walking in the countryside or spending time with animals. My friends, family and children are the most important thing in my life. My dad has AS and he understands me better than anyone else. He's an indispensable friend through the hard times. At the same time, my husband and friends know, understand and support me. What more could I ask for? My children are the driving force of my life.

I found out about this competition browsing through the LIRE website. I really wanted to give my point of view on living with AS because everything you hear about AS is told from a somewhat depressing perspective. Even though it's difficult, learning to live with the condition isn't that terrible.

**I suppose my story will vividly recall situations that people with ankylosing spondylitis (AS) will be familiar with. I'm certain that many people will be able to identify with my story.**

It was the summer of 1996 and I was a sporty girl right in the middle of my teenage years when I was involved in a serious car accident that prevented me from living a normal life for years. As a young girl, I could never have imagined the amount of traumatological and aesthetic surgery I would have to go through, and I later blamed this for the pains I experienced.

As my father has AS, anyone would think that I would have been diagnosed quickly when I started experiencing pain in my hips, spine and cervical vertebrae. Nothing could be further from the truth.

To be honest, when you're a child and you've seen your father in pain and have experienced first-hand the restrictions AS can have on someone's life, you feel certain of one thing and one thing only: that there is no way I am going to go through that. I had two other thoughts

that I clung to. Firstly, I was a girl: my brother didn't have the condition, so I was much less likely to get it. Secondly, I could pass off any signs of the condition as the after effects of my accident.

***"Worse things could happen"***

I started getting pains. The pains came and went, so I just thought: it's fine, no doubt it'll pass... It's just temporary and there are worse things that could happen. When I started getting pains in my spine, I thought: it's normal... I have bad posture when I walk and I must be putting pressure on my spine. When I started to get pain in my cervical vertebrae: it's normal... I'm tired from working on the computer all day, this happens to everyone. When I started getting pains in my spine: I must have been from doing too much sport (in those days, there were sports that people with AS should not take part in like lifting weights or doing exercises without any professional supervision). I just thought that, one day, I would be able to keep the "damage from the accident" under control.

As time went on, things got worse and the pain wouldn't ease. "Look Vanesa," our family doctor said to me one day,

"perhaps it's time to consider that there is a possibility you might have the same condition as your father, which from my point of view, wouldn't be the most ridiculous assumption." But I absolutely refused to accept this and tried other treatments, from homoeopathy to physiotherapy... All to no avail.

My physical condition kept getting worse and, with it, my emotional state. I was exhausted. I didn't want to do anything and I found it difficult to concentrate on work. Someone told me about fibromyalgia and, at that time, it seemed logical to me that this could be the cause of my problems. If there's one thing I can say, it's that I was never short of optimism! I decided to go and see a rheumatologist. After a 30-minute consultation and examination, her conclusion was as follows: "All I can tell you is that right now, you don't have fibromyalgia." I don't know whether I was relieved or disappointed because the realisation of the alternative crept over me: I would have to be checked for AS.

My father came along with me to the rheumatology department. As I told my story and saw the knowing glances that were passed back and forth between my father and the doctor, I realised that the doctor was certain of the diagnosis. Of course, she had to wait for the test results before confirming anything.

## ***"Biologic medicine has given me a break"***

And that was the moment that I thought: "Wow... I can do this. I'm doing so well! It's just a bit more exercise". But if life has

taught me anything, it's that it's not always a good idea to build up a tower of positivity and refuse to recognise a problem — when the tower falls, it comes down with an almighty crash.

After treatment with anti-inflammatory drugs, I went on to biologic drugs which worked quite well for some years. They stopped making it a few months ago, so I'm changing treatments. I hope it works, I'm sure it will! What I can be sure of is that biologic medicine has given me a break. We might not know what long-term effects it will have yet, but what does it matter? We want to be OK now, while we can still move — even if we move like robots!

My experience with my "live-in partner", as my dad and I call AS, is as follows: given that we'll live together forever, we need to understand each other. Sometimes the condition gets the better of me. But many other times (and I say that with the little bit of optimism I've managed to win back), I manage to overcome the condition.

I can't say it's easy living with AS... When you wake up on all fours in the bed and your children are shouting: "Mum, help me! Mum, do my hair! Mum, tie my shoelaces!"; when you have an operation on some part of your body and recovery is slow; when you're not even capable of giving your daughter a bath and you hit rock bottom... But then you pick yourself up again and it's time to move on! On these occasions, you need something to cling to. I am lucky enough to have the best husband in the world who is always on hand and lets me lean on him without

asking anything in return so I don't feel useless. I have my father, who knows exactly what I'm going through, and my children who always seems to have a smile to spare — even when I don't think it's possible they have any left. Family is essential. They don't have the support they need but they stay strong because they have to. My pets are also important to me; their silent presence, those walks with my dogs and the way they look at you, loyally and lovingly.

## ***"Some things were missing from the beginning"***

Without going into too much detail, one thing is certain: there are some things that were missing from the beginning which continue to make my life complicated even now. I'm sure many people with AS will agree with me when I say that these things often hurt more than the pain which you learn to live with. These things include:

- Lack of support in the workplace. When you're young and you want to continue to have an active working life, you don't have any protection. The "right to time off work" is a myth and, if you do get it, they make your life very difficult when you eventually go back. If you need to get up from your computer more than your colleagues because you're getting stiff, it's frowned upon. If you put all your files on a shelf where you don't have to stoop down to reach them, it's frowned upon. If you need a "special" chair, it's frowned upon. I can't count the number of times I've said to myself: "I wish I was missing an arm or a leg!" At least then the people around me would understand my

limitations. AS is a hidden disease so you need to stay in your seat like everyone else, use the lower shelf to store your files if you don't want to be seen as a weakling, a wimp or "making a fuss" at work. NOBODY helps us in this respect, so what's the alternative? Ask for disability leave? It isn't fair.

- On the other hand, I often felt I was lacking psychological support. Someone from the rheumatology department who knows what's going through your head when you are living with this condition rather than having to be referred by a doctor, tell them everything, be prescribed medication and then be referred to a psychiatrist before realising, on your second visit, that they still haven't realised that you can't stay sitting in the same position for a whole hour. If they don't know that much, how can they help you with everything else?

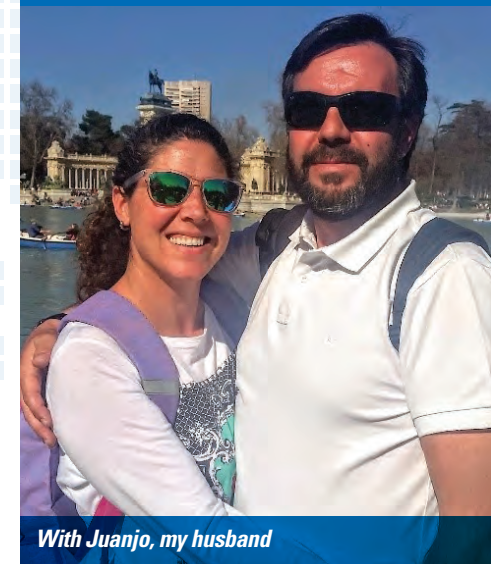
- We need rehabilitation treatment, and we all know I'm not talking about that little TENS light that doesn't do anything. We need "manual" treatment, which isn't covered by social security. Sometimes you have to prioritise the things that work. One day, these issues won't stand in our way any longer.

So now I've described my experience with my "live-in partner" to you, let me finish by saying this: it's not the worst partner you could have, so you need to learn to get along well together. Remember that it could be much worse, so why not move onwards and upwards? Let's do it!



*My little donkey Perdigón*

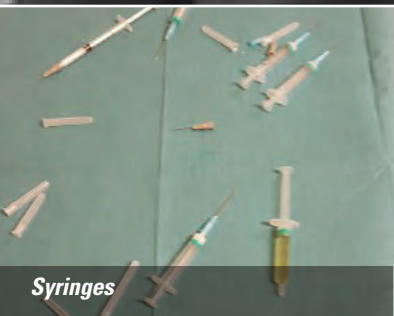
## **Ankylosing spondylitis: My personal story Vanessa Yuste Aguado**



*With Juanjo, my husband*



With my father



Syringes

**Najah di Zazzo**  
Sweden



Keeping positive while receiving treatment in hospital

# Living with a rheumatic disease

**I live with my family in a small town called Arboga. My family consists of my dad, Jack, my mom, Gabriella, and my elder sister, Ninell. We also have a dog called Balder. We live a little bit out of town but it is not far from the city centre.**

I will soon turn 17. In my leisure time, I play handball and spend time with my friends. One of my greatest pleasures is to travel and discover new places. I attend the Hotel and Tourism programme at my school, Vasagymnasiet.

I chose to write my essay because I hardly talk about my disease to people and have, therefore, never spoken or written about how I really feel. It felt great to sit all alone and just express myself, knowing that others will read it later.

**Lying on the stretcher, I see a computer, a board and a table with a green cloth covered with various syringes. There are also two doctors in the room who specialise in rheumatology.**

There is even a nurse standing on my right – she is calmly saying sentences like “look at me and keep breathing”. To my left sits the man who’s always there for me in situations like this – doctor’s appointments, courses, exercises, injections at home and reminding me about tablets. It is he who slept at the general hospital with me when I stayed overnight when I was younger; he who, to this day, goes in and sleeps where I am when he knows that the pain is at its worst. My father. My beloved father.

He sits holding my hand when I breathe nitrous oxide, and the nurse repeats “breathe Najah, breathe”. When the nitrous oxide has started to work, the difficult stuff starts – the injections. A burning sensation. I remember how I’ve long-described the sensation as being like a small drill entering the joints. It is

uncomfortable. The pain and discomfort are still there, but the relief is that the next two to three months will be pain-free. It feels as though the rheumatic disease disappears for a short while, as though I’ve never had it and as though other people of my age haven’t the least idea what it entails. And this is an insight into my life, what it’s like to live with a rheumatic disease.

I’m a 16-year-old girl who has lived with rheumatic disease since birth. I gradually found out that my parents thought it might be rheumatic disease because I was falling over and limping on a daily basis. As early as preschool, my six-year-old friends pulled me around in a cart and, every time we went for a walk, I was in a pushchair pushed by my preschool teachers. When I started primary school, I rarely joined in with walks and, if we were going on a trip out, I went by car with the teacher whereas the other children walked.

***“It was possible to play handball without running”***

I’ve always liked sport but, after having tried out many different types, I decided that handball suited me best. I quickly



realised that I couldn't run very much, which is something that you have to do during a handball match. The will was there and I would definitely have managed it based on my great stubborn streak, but the hours, if not the days, messed me up. Yet the stubborn me realised that it was possible to play handball without running – as goalkeeper. So I became the team's goalie. I've always wanted to be at the centre of things and always wanted to play handball, so it's a fantastic combination for a girl who isn't afraid of the ball.

I see my rheumatic disease as a friend. Sometimes it gives me strength and sometimes we are at loggerheads. Many times my disease has made me anxious and has made me question "Why me?", "Why do I have this?". Once, at primary school, a few friends and I didn't attend class and played ball instead. The ball flew away and I ran off to fetch it. When I came back, a boy asked how come I walked and ran so awkwardly? I usually had difficulty walking and running because there was a big difference between the length of my legs and the pain was almost greater. The answer I gave was that I had a disease: the boy looked at me and raised his eyebrows. I remember feeling uncomfortable and I took hold of my friends' arms and went inside – like the leader that I was or at least thought I was.

Throughout my school years I've been the one who takes part in all discussions, although I'm not the one to start them. I can't bear to see a person being nasty – I have to criticise that behaviour, which

has made the person think that I interfere in problems which are not mine. Either way, the meetings with teachers and, sometimes, headmasters haven't been difficult for me since I always stand up for what I've said and done. Now let's get to the point: during these meetings with headmasters and teachers, other pupils have said things like "they daren't condemn you because you have a disease" and "you get everything served on a silver platter because of your disease". This has saddened me the most because I would never lie or exaggerate my disease to gain sympathy. Quite the opposite – I mention it briefly, I avoid talking about it and people rarely hear me complaining when I'm in pain.

One situation I remember in particular happened when I was 15 and at a camp. The camp involved staying overnight in a tent, swimming in the lake, sitting by the fire and all the things you weren't supposed to do – like running outside at night being chased by the camp's night watchmen. The weekend came and, I must say, that my rheumatic disease wasn't at its best. I insisted on going against my parents' advice.

Sleeping on a thin mattress for one cold night didn't make matters any better. I asked my friend to help me up since my knees gave way when I tried myself. I limped to breakfast and got through the day with tablets which my parents had sent with me. We had decided to wait until this final night to run around outdoors because there was a risk of being sent home or having to wash up

the following day – you travel home fairly early on the Sunday so there was no risk of ending up washing up or being sent home. The evening came and I said that I couldn't go with them to run. My friend hugged me and took it well, but I certainly didn't. I was very sad. Lying by myself in a cold, dark tent with a mattress no more than 5cm thick – and very homesick into the bargain – was one of my worst night's ever. Things didn't get any better when I heard whispers and laughing outside from the other youngsters who could actually run. I could hear how they were enjoying themselves and how exciting it was.

## ***"I could never have managed without her"***

As I mentioned before, my father has played a big role in my life, just as big as my mother. She hasn't been there at the doctors' appointments but she has given me enormous support from home – support which nobody else has given me. She's understood me. It's difficult to explain the way in which she's helped me, but she's simply been there for me and made my daily life easier in a special way. She's brought me food after training sessions, prepared my bath after school, helped me to tidy my room, fetched this and that, and given me a lift in the car to various places although the distance is sometimes less than a few 100 metres. I simply could never have managed without her.

My mother has also been very good at reminding me about medicines and tablets. In one week, I take one injection

in the stomach, a single disease-modifying tablet and I take anti-inflammatory tablets at least once per day. I take the injection and the single tablet on Saturdays because it makes me feel very nauseous for around 24 hours afterwards. If I feel ill on Sundays, then school isn't affected.

As I said, the doctor's appointment I spoke about earlier is how a doctor's appointment goes when I need to be injected with cortisone. When I was younger I was sedated when this took place. But living with rheumatic disease means many more appointments. Orthopaedists, regular check-ups, blood tests, physiotherapists, aqua aerobics, dieticians, dentists etc. This takes many hours, but I know it'll be worth it. Ever since I developed my disease, I've hoped to get rid of it but, until then, my fight will continue.

Two concepts which I strive to live by every day are that you must always make the best of your situation and that everything happens for a reason. My life with rheumatic disease isn't a bed of roses, but nor is it something I want to complain about when you compare it with the outside world. It's just a matter of continuing to fight and realising that it isn't my fault and there's nothing I can do about it. As I said earlier, I see my rheumatic disease as a friend. Sometimes it gives me strength and sometimes we are at loggerheads. What I've written above is a summary of my life as it is now – this is my story so far. This is what it's like to live with rheumatic disease.

*First visit to the hospital*



## **Living with a rheumatic disease** **Najah di Zazzo**



*Eating breakfast sitting in a wheelchair*



**Fleur Farrell**  
United Kingdom



*Making a hand-tied posy on floristry course*



*My dogs Troy and Lucas*

# More than my disease

**I was diagnosed with rheumatoid arthritis in June 2016 at the age of 46. I live in rural Herefordshire with my partner David and our two dogs and two cats. I work as a social care commissioner in children's services specialising in child mental health and disability.**

In my spare time, I collect old photographs and give talks on how to date and interpret family photos. I am about to start a course in floral design and am planning to grow my own flowers for cutting this year.

I learned about the Edgar Stene Prize through the National Rheumatoid Arthritis Society newsletter. I wanted to share my experiences so that professionals and health commissioners get a better understanding of the realities of patient care. I hope this may help improve practice on a day-to-day basis.

**I press my body even closer to the unforgiving rock and try not to look down. "Grab the rope, grab it now," yells my climbing partner. "I can't, I can't move my hand," I yell back. I lose my grip and start to slide down the mountain side. The rush of cold air takes my breath away as I tumble faster and faster until, with a crashing jolt, I hit the valley floor... and wake up.**

For a moment, I am disorientated but the sense of relief at this being a dream is soon replaced with a rising sense of panic. I cannot move the fingers of my right hand. I switch on the light. After 20 minutes of furious waggling I can just about get my thumb to bend, but with a nauseating crunch. I drift back to sleep not realising this is my first encounter with a disease that will take over my life for the next year.

I decide to visit my doctor. Like me, he thinks I have strained my hand but decides to send me for blood tests anyway. Two weeks later I get a call. The doctor pauses for a few seconds then says: "Tell me, have you a family history of rheumatoid arthritis?". My heart sinks. Yes, yes, I do. I know all about rheumatoid arthritis – my grandmother had it. Diagnosed at 46, the same age as I am now, her deformed and swollen hands are an early childhood memory. "I think we will get you a rheumatology referral then," he says quietly.

***"The honeymoon period soon ends"***

So far this seems like an ideal scenario in the care of rheumatic disease. I visited my doctor as soon as I noticed my symptoms and I am lucky he considered all the possibilities and acted accordingly. The honeymoon period soon ends however when I receive my appointment date for the rheumatologist. It is for 10 December – five months away. Now even I know this is a disease where early diagnosis and treatment are vital. I call the hospital



and find this is normal in my area where waiting times for an initial consultation are anything between four and six months. I ask if there are any cancellations, but I am told these are reserved for existing patients. This is problematic when early treatment is crucial to limiting the damage this disease can do. I persevere and get an earlier appointment for September.

When I arrive, my consultant is sympathetic. Yes, I do have rheumatoid arthritis. How could I have not noticed my swollen joints, she asks? Numerous leaflets are thrust at me. I am told to ignore the frightening bits in them. These leaflets though are no substitute for the meaningful face-to-face discussion the short 40-minute appointment does not allow.

I am told to call the hospital rheumatology helpline if I need more information. I soon discover this helpline is an added source of stress. I call it on an almost daily basis as I prove unable to tolerate any of the drugs initially prescribed. It is open for just one hour a day and is the only way to contact the hospital. It is permanently engaged.

## ***"I am receiving no treatment and the disease rages on"***

It is decided to offer me injections rather than tablets. The delivery of the pre-filled syringes has been outsourced by the hospital to a private company. There is a six-week delay whilst the paperwork is passed back and forth.

Without the injections, I am receiving no treatment at all and the disease rages on. Eventually, four months after being diagnosed and six months after first seeing my doctor, my treatment is resumed. By this time it is too late. I am off work, unable to drive or do even the basics.

In the intervening time, I have received appointments with physiotherapists and occupational therapists and have been asked to join a patient education programme called "Taking Control of Inflammatory Arthritis". This programme will teach me how to live with my condition, understand the drugs I am on and manage my pain. It sounds like just what I need. It seems my area has a good, well thought out patient pathway for inflammatory arthritis – very different to when my grandmother was diagnosed in 1956 and sent away with just a packet of aspirin.

It is also painfully obvious, however, that what looks good on paper does not always work well in practice in a health system stretched to breaking point. I must wait months for each appointment. I am offered a place on the programme seven months after my diagnosis. That is seven months of trying to cope with the dismissive reactions of friends and family who do not understand the disease. Seven months in which I am free to Google my medications and their side effects. I find the internet awash with "my life of methotrexate hell" horror stories and

articles urging me to change my diet and cure my condition by tomorrow. What I desperately need in these first few months is someone to help me separate fact from fiction. I need perspective.

My rheumatology nurse recommends I join the National Rheumatoid Arthritis Society. I'm glad I do. They balance those internet stories for me with the real facts. They also offer me booklets to give to my family and my employer so that everyone gets a better understanding of the challenges I might face, especially in this first year.

## ***"They balance those internet stories with real facts"***

Before my diagnosis, I had planned on leaving my desk job for a more physically demanding one as a florist. I remember asking my occupational therapist about this. She looked doubtfully at me and suggested perhaps I shouldn't be thinking about making any changes... just yet. The loss of hope that I sense in many professionals when they hear my diagnosis is hard to cope with. It reminds me of the complaint I hear most from the parents of children with disabilities I work with: why does everyone concentrate on what their child cannot do instead of focusing on what they can? Everything about my treatment seems to revolve around the physical problems my condition might bring. It ignores the emotional issues of having this diagnosis, especially the

impression of being written off when you feel you are only half way through your working life.

## ***"I am more than just my disease"***

Over the last year, I have learnt a lot. I have learnt that an early diagnosis in a hard-pressed health system is no guarantee of a better outcome. I have learnt that when commissioners are designing new care pathways they need to consider all the factors that may affect its success rather than just concentrating on clinical need. Above all I have learnt I cannot let my condition, or the assumptions of others, dictate what I can achieve.

I have put my name down for the floristry course I was planning to do before my diagnosis. I do not know whether I will complete it, but if I don't try then I certainly never will! I do not know what the future holds, but what I have learnt this year is that I am still me and I am much, much more than just my disease.

*At home in rural Herefordshire*



## **More than my disease** **Fleur Farrell**



*In the garden*



Maria Prodrinou



Eva Czechová



Maiken Brathe

# Meet the other essayists

## Cyprus

**Maria Prodrinou**  
Larnaca, Cyprus

The fact that my diagnosis was not timely, and nine months passed before I received medication, deprived me of many things. I caught myself wondering what my life would be from then on. Could I have a normal life? Could I have a family with all those strong medicines I was taking? I tried to banish these thoughts.

Here I am today, at the age of 36, married to a wonderful husband, and with two adorable boys aged two and three and a half. There are times my fingers get swollen and become stiff, and I can't even hold or hug my babies. There are many times that I can't do any housework. But I know that, in a few days, it will be over. And the most important thing is that I have my husband and my parents who support and help me through these challenging days.

## Czech Republic

**Eva Czechová**  
Opava, Czech Republic

Would anything be different today if I had not fallen into the hands of a rheumatologist when I was 17 years old? Maybe I would have lived happily and contentedly, not affected by the volume of medication and chemicals that I have put into my body since then. My body would have fought and achieved a balance. I would have lived happily and pain-free, ever after... But I think we all know that is just a fairy tale.

It would have been more likely that I would have stumbled through my days always tired, swollen, dehydrated, in pain. No one would have restrained my perverted immune system and pushed it back past the limits it belongs behind. My illness would have progressed more quickly. I would not have known why I felt so terrible, and this would have probably made me very nervous. The more nervous I would have been, the worse off I would have been physically.

## Germany

**Maiken Brathe**  
Hamburg, Germany

When I think of my feet, I often feel sad because they cause me lot of pain... or furious, because they refuse to co-operate when I feel like dancing.

Recently, my chiropodist said to my feet: "Wow, you look great!" and I thought she was making fun of me. But then she explained how some people's feet have given up walking altogether. Feet that are confined to badly-fitting shoes, either to protect them or hide them away. She explained that my feet, on the other hand, were brave, kitted out in high orthopaedic boots.

There are some people who make fun of my orthopaedic shoes or the way that I walk. But I didn't choose to be ill. I have to go through every day knowing that my feet could break. But I still go out every day and enjoy the day; enjoy my life.



# Meet the other essayists

## Poland

### Tatiana Gurgul

Jastrzębie Zdrój, Poland

The doctor's role is to advise patients on their condition, treatment options and side effects. The patient must be aware of what is happening and why. Frequently, patients look for information and help wherever they can. It was the case for me — I started acting like a detective, looking for a solution, a way to help myself.

It is too bad that doctors do not tailor treatment to the person, only to the disease entity. They do not consider the patient's opinion. Of course, doctors act in line with the treatment guidelines of a given condition — this is understandable. However, sometimes that is not enough. To understand why something is happening, it is necessary to understand someone's history, find the cause and listen to what the patient has to say. Sadly, there is no time for this in our healthcare system.

Fortunately, there are wonderful doctors who give patients their time — doctors who really want to help the person in need.

## Serbia

### Andjelina Arsenijević

Belgrade, Serbia

As a gift for my 15th birthday, Nikola (my stepfather) gave me an opportunity to be a co-pilot. I couldn't stop crying and laughing with joy.

Many happy thoughts, ideas and a big realisation occurred during that half hour flight. After so many years, nothing hurt — not one joint or finger — and, despite my left eye, I could see all the beauty of this world. Those magical moments made me feel like a bird — free to live life to the fullest with each part of my body. I decided then that, when I grow up, I will be a pilot.

In my ideal world (a world without rheumatoid diseases), when I become a pilot I will fly a plane of happiness. My passengers will be exclusively children. On board, many ideas will be conceived, and many unrealised dreams will live. The only thing I would like to ask you for is a license to fly to a much more beautiful, painless world.

## Switzerland

### Bettina Immler

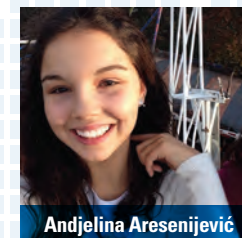
Buchs, Switzerland

There's no doubt that the 11-year ordeal seeking a proper diagnosis and trying to find the right treatment has had a negative effect on my health. There is constant emphasis on the importance of early diagnosis and treatment for long-term health benefits. Unfortunately, year upon year of following a therapy programme that simply wasn't right for me has left its mark on my body.

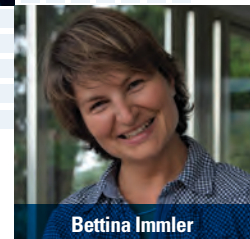
As a result of blocked joints on an almost daily basis, my tendons and ligaments have become looser. How much the new therapy will help to get these problems under control remains to be seen. Despite these difficult facts and unpleasant circumstances, my quality of life has significantly improved thanks to this new rehabilitation treatment. Through core training and Pilates, also known as segmental stabilisation therapy, I have found a helpful remedy for the instability in some of my joints. This improvement in stability and stamina has given me a new freedom that is invaluable to me!



Tatiana Gurgul



Andjelina Arsenijević



Bettina Immler

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fighting rheumatic & musculoskeletal  
diseases together