

EDGAR STENE PRIZE 2016



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Living with a rheumatic or musculoskeletal disease –
How I take action to
enjoy life to the full



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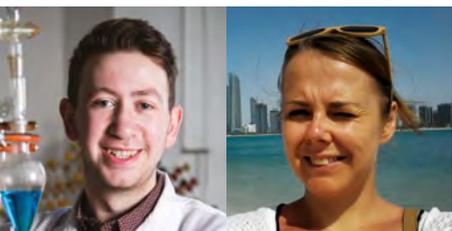
eular

Standing Committee of People with Arthritis/Rheumatism in Europe (PARE)

2016

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

STENE PRIZE BOOKLET 2016

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The Standing Committee of PARE would like to thank all those who have contributed to this publication.



Early diagnosis and access to treatment are key to enabling people with RMDs to live life to the full

It is a pleasure and honour to have been asked to write the introduction to one of EULAR's most important and valued publications – the 2016 Edgar Stene Prize Booklet. The series started in 2009 and I am delighted to present a new and refreshed design to our readers with this 8th edition. I am proud to share it – not only is it popular within our own community, but it is also highly valued by policy makers and other key stakeholders at the national and European level.

This year's topic was titled "Living with a rheumatic or musculoskeletal disease – How I take action to live life to the full". We have received contributions from 20 member organisations, and it was great to hear that this topic has been highly popular at the national level. The large number of contributions is very encouraging as it shows that it is possible for many people to live a full life despite suffering from a chronic disease.

For the first time EULAR is not only awarding a single winner but also officially the second and third ranking essays, which is a great achievement. For me though, all those who have participated are winners and have my admiration. They have shown a lot of courage in sharing their personal story, dreams and feelings with the world. Their honesty, vulnerability and humour makes it possible to relate to them at a very personal level, and I have been deeply touched.

As a rheumatologist, I find it most rewarding to play a role – together with my team – in helping my patients to get their lives back. This was the reason why I chose this profession in the first place. Many of the essays tell how the most important step on this path is to quickly get the right diagnosis in order to start treatment as soon as possible. But we know that it often takes too long to receive the correct diagnosis in most countries in Europe. People suffer unnecessarily and are not treated appropriately – thus, valuable time is lost. This is damaging to the individual on a personal level and to the healthcare systems. For some conditions, like rheumatoid arthritis, there is evidence that, if treated early enough, the otherwise severe disability can be prevented and the person affected can also continue to contribute economically to society.

We have some powerful treatments available today, but access is often overregulated and, in some countries, extremely limited. We need to make decision-makers understand that prevention, early diagnosis and access to the appropriate treatments save costs in the long term. These essays show us, in a powerful way, what really matters to people with RMDs and what issues need addressing most urgently.

EULAR is, of course, addressing these important areas in many of its existing projects and campaigns. We will be fighting for early diagnosis – together with first and secondary prevention – over the coming years, as it is vital to improve the final outcomes. EULAR offers a platform to all those who share this vision – for those who want to see a better quality of life for people with RMDs and to enable them to live their life to the full. It is the engine driving EULAR's work, but it needs to be recognised and acted upon at the national and European level by politicians, key decision-makers and society.

I would like to sincerely thank all those who have participated in the competition for sharing their personal approach to how they live their lives – how to cope with the diagnosis, the daily pain, the barriers, the fatigue and many other challenges. I was impressed by their positive attitude, strength and joy for life despite the burden of their RMDs.

I am sure that their great insight and knowledge will be shared widely and will help all of us to improve the quality of life for the more than 120 million people living with an RMD in Europe.

Prof. Gerd-Rüdiger Burmester
EULAR President



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”.

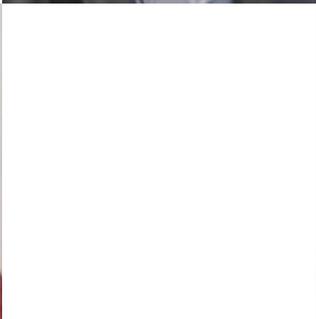
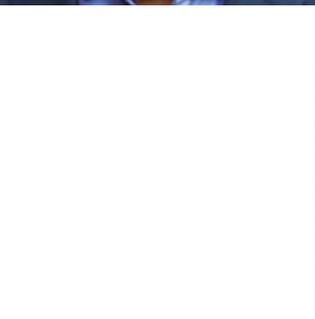
He advocated the union of people with rheumatic and musculoskeletal diseases (RMDs) in a specific organisation to provide a platform for effectively addressing the issues that concerned them. He also emphasised the importance of people with RMDs having an active and positive attitude towards their condition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

Rules of the 2016 Edgar Stene Prize competition

Every year, the 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 Stene Prize Jury.

For 2016, 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 EURO 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.



The Edgar Stene Prize Jury 2016 — 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, EULAR Standing Committee of PARE

“I was an adolescent when I was diagnosed with a rheumatic disease. When you are confronted with this diagnosis, and are seriously ill, you feel your whole world is breaking apart. All your plans for the future vanish, while pain and despair mingle and mutually reinforce. You feel you are in a dead-end street.

But with the competence of your doctors and your treatment team, and support from your family and friends, your life will soon look bright and positive again. Nowadays, new therapies enable a good outcome. You will develop your optimal treatment plan and adapt your activities and plans to the new circumstances. You will recognise the enormous chances where you can participate and be active.

Life is wonderful and, in spite of a rheumatic and musculoskeletal disease (RMD), it is possible to live a richly faceted life. And that is exactly this year’s topic. It was great to read your very personal stories about how you shape and enjoy your lives to the utmost.

I enjoyed reading your essays.”

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

“This year’s topic for the Edgar Stene Prize essay competition is very close to my heart. As a person living with rheumatoid arthritis (RA) for many years, I know first hand how important it is to take your life back – to control your future, live independently, be socially active, participate within society and enjoy your life to the fullest.

Living with an RMD is difficult because of the pain and other symptoms that often accompany the disease. It can be easy to withdraw from life, feel isolated and, finally, fall into an endless circle of pain and despair. Hence, when living with a rheumatic disease, it’s important to focus on what you can do, and not on what you can’t do.

It is also important to accept the new situation of living with an RMD. Sometimes this requires a change in the way you do things, your attitude and lifestyle, and retaking control and learning alternative – and new – ways to live life to the fullest despite the disease.

This year’s competition has given people with RMDs across Europe the opportunity to share their success story with us. These essays will, I am sure, inspire and motivate all others, and also show that, with the appropriate support, people with RMDs can live a full life with dignity and quality.”

3. Nele Caeyers, PARE Board member from Belgium and spokeswoman for ReumaNet, is Leader of the 2016 Edgar Stene Prize Jury

“As a child, I enjoyed being outside with friends, running, playing, camping... I really did enjoy life to the full. And I planned to continue doing so, but along came lupus. All of a sudden things weren't self-evident anymore. Hospital visits instead of visits to friends, medical check-ups instead of social check-ups, walking instead of running, hesitating instead of going all the way.

But I soon realised I only had one life, just like anyone else. And I had a choice: disappearing or taking control again and looking for things I could still achieve and enjoy. Today, I can honestly say I enjoy my life to the full. My family, my friends, my job and my voluntary work are precious to me.

I am very happy with the theme of this year's Edgar Stene Prize competition. It forces you to look back at your life and your achievements. Maybe it confronts you with your limits, but, even more, it makes you aware of your abilities! Life is too valuable, too unique and, most of all, too short to not enjoy it to the full!

I enjoyed reading all your stories and have been inspired by them.”

4. Prof. Tadej Avcin, 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 how to overcome the burden of the disease and enjoy life to the full. Working as a paediatric rheumatologist, I observe patients during the critical transition period to adulthood, when they are especially vulnerable to the possible negative effects of their disease.

Successful life stories by people with RMDs are always encouraging and inspirational for both patients and physicians. Positive information about living with the disease is particularly important for young people in order to develop and enjoy all aspects of their lives.

Evaluation of the transition process from the perspective of young adult patients has revealed that counselling about their future, living with the disease, is one of the major perceived deficits in clinical care. In this respect, real-life success stories of patients with RMDs are precious and can provide enormous inspiration for patients and their families.

I really enjoyed being involved in the Edgar Stene jury. I have learnt, from the patient perspective, how to take action and live a happy and productive life. Reading the essays was a remarkable experience and very inspirational for me. All of the essays were very well written and it is extremely hard to highlight only a few of them.”

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

“My name is Wendy and I'm 21 years old. I'm on the board of Youth-R-Well.com, the Dutch association for young people with a rheumatic disease. I was diagnosed with juvenile arthritis when I was 14 years old. Currently I'm studying Industrial Engineering and Management at the University of Groningen.

It has been a great pleasure to be part of this jury and I enjoyed reading the essays from the different European countries. I think that the theme for this year 'Living with a rheumatic or musculoskeletal disease – How I take action to enjoy life to the full' has given us very different, inspirational stories. I read all the essays and they were all wonderful! I think they all have something inspirational and something that we should remember. I really enjoyed my task as a member of the jury!

As for myself, I think I enjoy life to the fullest by not letting my illness define me. Although you possibly cannot do everything you want, you can still do a lot when making a few adjustments. There are so many people in the world who are willing to help you. I think that, except for all the pain, my disease has also brought me really good things.”

6. Costas Ioulianos, Cyprus, President of cosmosrheuma+, representing the EULAR Health Professionals in Rheumatology

“Firstly, I would like to say how proud I feel to be a member of the Stene Prize jury panel. As a clinical physiotherapist – and due to my frequent involvement with people living with RMDs – I have come to the conclusion that there is an imperative need to involve the patient in all decisions concerning them and their life.

Since we talk about multidisciplinary and patient-centered treatment, we should support this – and with our actions. The patient should be the group leader and must be actively involved in order to solve and manage their problems. We have an obligation to feel/understand everything concerning the patient.

The problem is not only the disease, but all the other related problems that follow which have to do with the patient, their family, their occupation and, generally, their position in the broad community.

By taking part in the judging panel I have gained a lot from the patients themselves – a fact which is the most important element towards the success of our work.”

7. Kjerstin Fjeldstad, Norway, Board member of the Norwegian League Against Rheumatism

“It has been an honour to be a member of the Stene Prize jury and I have been inspired by the vision applicants have for their lives. This year's theme 'Living with an RMD – How I take action to enjoy life to the full' has given authors an opportunity to look at their lives and tell us how they have reached their personal goals. I enjoyed reading the essays very much.

I am 61 years old and spondyloarthritis (SpA) has been my friend the last 30 years. I still work, and I do voluntary work as well. I became involved in the Norwegian League Against Rheumatism 30 years ago. I have been a board member and leader in a different part of the organisation.

I work at the Norwegian Labour and Welfare Administration. I work full time, but have one day off every week for rehabilitation.”

2016
STENE PRIZE
WINNER

2015: 'Making a Difference' award winner for social responsibility at The University of Manchester, pictured with Professor Dame Nancy Rothwell, Chancellor of the University



Simon Stones
2016 Stene Prize winner
from United Kingdom



2016: at EULAR PARE Conference in Sofia, Bulgaria



Aged 12: living with active arthritis and undiagnosed Crohn's disease

A life without arthritis wouldn't be my life

Simon Stones is a 22-year-old student and patient research ambassador. He is single and lives with his parents, both of whom have multiple rheumatic and musculoskeletal diseases. His home town is Bolton in the Greater Manchester area of the United Kingdom (UK).

"I have lived with juvenile idiopathic arthritis (JIA), hypermobility and fibromyalgia from the age of three, and have helped to care for my mother who has systemic lupus erythematosus (SLE) and osteoarthritis. I am currently studying a bachelor's degree in biomedical sciences, and hope to do postgraduate research into child health.

As a consumer health advocate, I advise the UK's National Institute for Health Research, and Arthritis Research UK on their paediatric rheumatology research agendas. In addition, I sit on numerous strategic and advisory panels for health and social care initiatives in the UK, including the development of mobile app technology to promote self-management in young people with JIA.

I have recently supported the development of EULAR/PReS (Paediatric

Rheumatology European Society) recommendations for transitional care in young people with RMDs, and I sit on the EULAR Young PARE working group.

I began to work with EULAR Young PARE in 2015 to help give young people with RMDs a voice in Europe. I was at the annual congress in Rome when I learnt more about the Stene Prize and decided to take part. I chose to participate to share my story of living with arthritis and to inspire other young people to realise that they are capable of achieving their dreams."

I don't remember a day without arthritis being there. Always in the background... Wherever you look, whatever you do, it's there. Having had arthritis from the age of three, it's hard to remember what life used to be like.

I had a fairly "normal" childhood. It wasn't like that of my friends in school, but it was all that I knew. Arthritis took its toll on my young body, with constant hot, stiff and swollen joints. Life began to get much worse when I was prescribed

a new drug in 2000. For three solid years, I would suffer at the receiving end of this medicine. Weekends consisted of constant nausea and vomiting. I never experienced days out with friends. Even trips to the shops with my parents resulted in me lying down in the car feeling sick. I tried to explain this to my doctors, but they didn't fully appreciate the impact of this medicine on my life – let alone the impact of the disease in its own right.

"For the first time in years I felt like I was in control"

Life was pretty rough. I would go to school during the week on the days when I could physically get out of bed. I was exhausted in the evenings and spent the weekends ill at home as a consequence of the medicine. At the age of seven, what was the point in life? If having arthritis wasn't bad enough, the medicine to "treat" it felt like a punishment. I told the doctors at the hospital that I would rather be stuck in a wheelchair for life rather than take that drug. The light at the end of the tunnel had disappeared and all glimmers of hope seemed a million miles away.

A turning point in my life was in 2004 when, at the age of 11, I was switched on to a new biologic medicine. It was a miracle. After just a week's treatment with the medicine I was able to get out of the wheelchair and walk – without feeling sick, without agonising pain. It was unbelievable. Although pain and fatigue were there every single day, it was more manageable than before. For the first time in years I felt like I was in control.

“They had just ignited a spark within me!”

As a consequence of my inability to perform sports as a child, I had never been a huge fan of football! Instead, I had channeled my time and energy into learning – into being academic. My aim was to get to do my GCSEs (General Certificates of Secondary Education)‡ – but not just to pass them, I wanted to get the best! This seemed like a distant goal, and I was uncertain whether I would get there after having had to miss so much time from school.

In the years that followed, I was diagnosed with Crohn's disease and, in combination with arthritis, I missed an additional 12 months of school. As I began to study for my GCSEs, so many people said it wasn't worthwhile putting myself through this stress. They suggested that I should just get through the exams, accept whatever I got, and choose a stress-free job that didn't affect my health. However, they didn't realise that they had just ignited a spark within

me, which was going to prove them wrong. Nobody ever tells me that I am incapable of achieving my dreams!

With sheer drive and determination, I went on to study my GCSEs, pushing myself to the extreme. Given all of the pushbacks in life, nobody was going to stop me now. In the summer of 2010, I was over the moon when I achieved 13 GCSEs at grades A and A*. I then went on to sixth form college where I studied biology, chemistry, and physics at A-Level, achieving A and B grades in 2012.

It may not surprise you that, later in that year, I moved to the University of Manchester to study a degree in biomedical sciences. It was something I had always been interested in but, more importantly, was an opportunity for me to give something back to society – to help the people living with rheumatic and musculoskeletal diseases (RMDs).

“I wouldn't want to be perfect”

Going to university whilst living with arthritis, Crohn's disease and fibromyalgia certainly comes with its challenges – especially having had your confidence knocked out of you as a young person. As I have grown up, I've learnt to appreciate the small things in life – a loving family, great friends and embracing new experiences. Now, at the age of 22, I am in the final year of my undergraduate studies, and I am projected to achieve a 1st class honours degree in summer 2016 – something

which was just a dream in years gone by.

I have learnt to take life with a pinch of salt – on my good days I sometimes go mad and do as much as I can. Inevitably, I may suffer the day after – but, to me, it is worth it. I may not be perfect, but I wouldn't want to be perfect. I think it can take a number of years for you to reach this acceptance “phase”, where you can live beyond the limitations of your condition. I am more than capable of achieving what my peers can achieve. If I want to do something, I will do it – why should I not? Taking your daily medication, doing your exercises and having time out are part and parcel of your daily routine. You learn to adapt, and view all of the positives in a sea of negativity.

My personal experiences have encouraged me to help others living with RMDs, who have to deal with these horrendous conditions on a daily basis. I do this in the hope that, one day, people with RMDs will not have to endure the physical, social and psychological consequences of these diseases.

For the past three years, I have built on my experiences to become a patient research ambassador – campaigning for, and representing the voice of, young people with RMDs at a local, national and international level. In doing so, I have met many wonderful people and seen some amazing places around the world – something that I would never have done if I didn't have arthritis.

“Every person with an RMD is a wonderful, capable and unique human being”

Moreover, I have taken the decision to study for a PhD in the autumn of 2016. In doing so, I hope that I will be able to make a difference, and empower young people to realise their dreams, hold on to them and achieve them – because every person with an RMD is a wonderful, capable and unique human being.

Studying for a degree, advocating for patients and living with an RMD can, at times, leave you completely drained. But, funnily enough, I have never been happier. Life without arthritis wouldn't be my life – the one that I love. My experiences have shaped me into the person I am today, and I would never want to change.

I live for today and dream for tomorrow. None of us know what is around the corner but, when you learn to live the life you love and love the life you live, you've found true happiness. I keep fighting, I keep smiling and I enjoy every moment in this rollercoaster of a journey that is life.

‡ Editor's note: GCSE examinations are taken by most pupils at the end of compulsory school education (aged 16 years) in England, Wales and Northern Ireland.



Simon is now working to improve the lives of other young people with RMDs

**A life without arthritis wouldn't be my life
Simon Stones**



2012: receiving the 'success and determination' award after leaving Sixth Form College

2016
STENE PRIZE
2nd place

Triin Pobbol
2016 Stene Prize 2nd place
from Estonia

At an NBA Boston Celtic home game

I enjoy the outdoor life even if the weather is often wet in Estonia

Life shouldn't be sickly-sweet

I am 31 years old, single and live in Paide in Estonia. I work as head of planning and development in the Järva County administration.

I learnt about the Edgar Stene Prize from the EULAR website. The topic spoke to me and I decided to write an essay for the competition.

The shock

“Right, the blood test confirms my suspicions about the diagnosis – you have inflammatory polyarthritis,” my doctor told me one February morning a couple of years ago. His voice was matter-of-fact. Like he was telling me that my shoelaces had come undone and needed to be tied again. Or like drinking milk had given me a moustache that needed to be wiped off. He made it sound like something ordinary, something that happens every day. But the world inside me and around me collapsed, and it took me a long time and a lot of effort to pick up the pieces again. I left the doctor's in tears, knowing that I now had a tedious friend I'd have to drag along with me for the rest of my life.

Denial and anger, not to mention accusations

“I have polyarthritis?” I asked myself in the days that followed. I have it, even though there's no history of the disease in my family. I have it, even though I'm usually very careful about what I eat. I have it, even though I consider daily exercise a very important part of my life. There were so many reasons I just

couldn't have this disease. I kept hoping that they had mixed up the test results somehow and that the pain in my knee joints was actually caused by some small trauma.

Oh bloody hell, I thought next. I have it? I've lived my life so well and now you, some stupid inflammation, have come along to destroy my body? Oh, I was so angry. Angry at myself and everyone else as well. Why did I worry so much about work, often bringing it home with me? Why didn't I sleep enough? Why hadn't the doctors diagnosed it earlier so they could start treating me sooner? I'd been running from one doctor to another for more than a year until that day in February. Why?

Only you can climb out of the hole you've fallen into

“Look, Triin, your friend's outside and wants to talk to you,” my mum told me one Sunday when I'd been sprawled out on my parents' sofa for hours on end. How could she not understand that I couldn't, that I didn't have the strength? How could she not understand the effect methotrexate had on me, that I just didn't want to do anything? When I look back at the methotrexate period, I realise

I can't actually remember any happy events in my life at that time. I was under the influence of the drugs and in a big, black hole.

And then it came – acceptance. Acceptance of myself and my condition. Getting there had been difficult; there had been so many obstacles in my path, but starting biological treatment probably helped me the most. Once my health started improving, I started feeling better about myself. There isn't a single doctor – although my GP and the specialist who oversaw my treatment are both great and very helpful – who can help you if you don't want to help yourself. It's easier said than done. I worked hard on myself – I increased my physical burden even more, reviewed my diet and read some self-help books. I also found out that while I was trying to come to terms with having the condition and to accept it, I'd gone through the same phases that people experience when in mourning, trying to accept someone's death: shock was followed by denial, anger, blaming others, depression and, in the end, acceptance and returning to life.

I realised that the thing that helped me most was talking, sharing my experience, because I've always lived an active life – travelling, hiking, exercising. But I needed others to help me make things easier for myself.

Let's talk

I once ended up at a meeting of the local rheumatism society – they all go off together to discover an exciting new

place and then sit down with tea and cake to discuss anything that comes into their heads. When I said that I'd finally started biological treatment and it was having a positive effect on me, one of them looked at me, startled, and said that if I was getting biological treatment, I must really have rheumatism. Of course I have it, I thought in amazement. I realised the group wasn't for me, but I didn't stop "letting it all out".

Then I discovered that a very close friend of mine was battling the same disease, that she was also stuck in the vicious circle of methotrexate-prednisolone-methylprednisolone-biological treatment-stiff joints-weight gain. We started talking, and I felt like we both found comfort in it. To this day, we seem to share a secret language – the language of our disease – that nobody else understands. But I know that there's at least one person who knows exactly what and how I feel. It gives me so much support.

As I work in management, I always need to be on form and cheerful. But how can I when every morning my body is in pain when I get out of bed? After hiding it for a long time, I decided to be honest. First of all, I told my boss that no matter what he thinks, I have to go and see the doctor from time to time and I also need days off to get over the exhaustion. I also told my team that if I sometimes come across as grumpy, it's because I'm not feeling that great. Instead of the pity I feared I was going to get, they looked at me with understanding, support and

admiration... and told me that they applauded me for my bravery in handling it all so well.

And, my dear friends – I really love to hike. But how can I go hiking with a friend who just takes the first path into the forest and definitely plans to jump across a ditch somewhere? I spoke to her, and the next time we went hiking she stopped and waited for me at every obstacle, helping me without saying a word. I like how my friends give me a helping hand without even realising they're helping me.

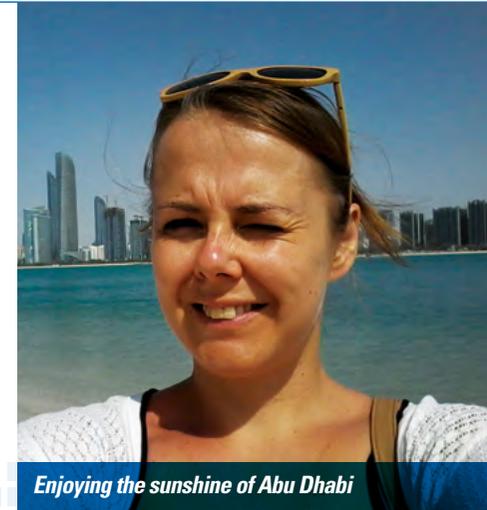
Everything was even more complicated with those closest to me. My parents also had to come to terms with the knowledge that their daughter had a tedious disease, and I could see that accepting it was hard for them. I once sat them down on the sofa and told them everything, my entire case history, and how I felt on good and bad days. I emphasised that I was feeling a little better every day and that modern medicine had the ability to help people without the drugs causing too many complications. It got easier. For them and for me.

Back to life, back to reality

Now, three-and-a-half years after I noticed the first signs of the disease, and almost two years after that life-changing morning at the doctor's, I'm back in my reality. Sure, there are times when I end up back in the phase of denial, anger and accusations, when I get a bit depressed. But then I quote

one of my acquaintances who likes to say: "You can't have only good things in life, or it would get sickly-sweet."

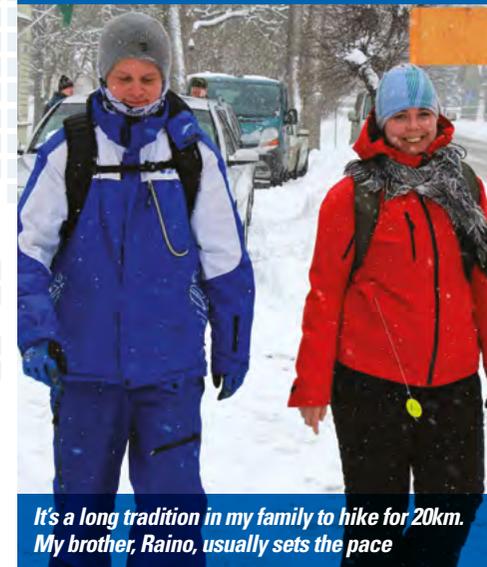
So thank you, disease, for existing and not letting my life get sickly-sweet.



Enjoying the sunshine of Abu Dhabi

Life shouldn't be sickly-sweet

Triin Pobbol



It's a long tradition in my family to hike for 20km. My brother, Raino, usually sets the pace

2016
STENE PRIZE
3rd place



After my first running event following diagnosis



Dana Berga
2016 Stene Prize 3rd place
from Latvia



With my friends

You don't have to stop, you don't have to give in!

I am a single 26-year-old living with rheumatoid arthritis in Valmiera, Latvia.

I learned about the Stene Prize competition from members of the Facebook group "Life with Arthritis" in Latvia. I decided to take part as I thought the process of writing would serve as a mini self-psychotherapy session and help me collate my thoughts on the subject.

I work as an English language teacher. The deadline for sending entries coincided with the school holidays, when I have much more free time as a teacher. It was a challenge, because I haven't done anything like this for two years.

Of all the essays I've ever written, this will be the most difficult physically. On the day I'm writing this, my fingers are stiff and slightly painful ("Murphy's Law?"). My name is Dana and I am an English teacher with rheumatoid arthritis.

The joys of life and optimism have been part of me for the entire 26 years of my life, but I've had rheumatoid arthritis for only 1.5 years. I'm still learning to live with it, as though it were my invisible friend. I don't want to say that my enemy lives within me, so that's why I call it my invisible friend with whom I want to coexist peacefully.

How can I stop myself from thinking about my illness every waking moment? First of all, those who love their work are the lucky ones, because that's where they spend 1/3 of the day. I'm fortunate in that I like being a teacher who helps understand, explain and inspire. Being a teacher is my

calling and, at the same time, my hobby... To be amongst young people and quietly hope that a certain pupil could become the next president or a doctor, or that another might turn out to be a good author or an actor.

"I see the finer details in the everyday"

I try to keep myself busy wherever possible with things that inspire me, make me happy, calm me down and free me... To be carried away with the smaller things in life. I find delight in the little dog that takes a sniff of me, or from my neighbour's flowerbeds and children chattering. I see the finer details in the everyday and don't take them for granted. I regard my invisible friend, arthritis, as a never-ending lesson that I should spend more time looking after myself rather than worrying or become stressed about insignificant matters. I should take more enjoyment in a sunny day, rather than chase every speck of dust I see at home. I have to allow myself not to do things and not feel bad about it. I have to learn to say "No!"

The presence of rheumatoid arthritis destroyed my optimism. At the start, my illness was sudden and severe, both physically and mentally. The initial diagnosis seemed as dreadful as being diagnosed with cancer. Everything seemed hopeless and tragic.

Nevertheless, there are always two options – either give in and moan, or shake yourself down, both physically and mentally. During the first months of my illness I chose the first option, but then I realised that this was not how I wanted to spend the remaining 50+ years of my life. All that remained was for me to find a way to improve the quality of my life by setting aside time for my hobbies – running, hiking and choir singing – and to take more care of my body, mind and soul.

“I’m overwhelmed by the feeling that I can do everything”

Being outside in the forest or a meadow or marsh has always been important for me. I grew up in the countryside and every day I feel the need to be closer to nature, rather than

buildings and people. That is why I moved from the capital to a small town this summer. Weekly hikes with my friends are just as commonplace as brushing my teeth. It may be self-evident, but if I don’t do this I feel a certain degree of discomfort. The forest calms me. I can’t fly to the moon to see how small the earth is and how microscopic my problems are, but in the forest I’m overwhelmed by the feeling that I can do everything.

The illness will not defeat me – I only need to discard the egocentric notion that “I’m in pain” and focus on “I don’t want to be in pain”. Nature inspires and calms me. When I’m outside I don’t feel any pain, because there are other thoughts in my head, such as “What type of bird did I hear or see? Look, can you see an animal’s footprints or the animal itself? What’s that pile of conifer needles?”

I often combine my time outdoors with my second hobby: running. When I run I exceed myself and my abilities, especially when I want to run more than initially planned. I set the finish line at “that tree” but, when I approach it, I say to myself “run a bit more”.

This is followed by an erupting volcano of endorphins. Because I’m proud of another small win. My friends support me when I run long-distance competitions. They know I won’t be able to run 20+km as before, but I can – and want to – run 3-10 km.

“Choir singing is my form of yoga”

My third hobby isn’t related to the others, because contrary to the Latvian saying “Don’t shout, you’re not in the forest”, I don’t sing in the forest and I tend to be quiet. My parents were always respectful of the fact that we are just visitors in the forest, and that’s what they taught me. But now I sing in the mixed choir “Valmiera”. The choir is friendly and at times we tease each other. I could say that choir singing is my form of yoga. The choir offers respite when I’m worn out at the end of a working day, and this is “me time”. When I sing I can relax and free myself. All my tense and painful joints are relaxed and I feel far better after a three-hour rehearsal. I feel recharged and full of life.

The German novelist Erich Maria Remarque said that “You can never become hardened. You can only become accustomed to many things”. Well, you can learn to live with an unwelcome diagnosis or disease, with minimal impact. But when there is pain you shouldn’t try to be super human – you have to allow those around you to provide help, and if you’re unable to do something you should say so clearly and not be scared or embarrassed about asking for help.



With my soon-to-be husband, Jānis

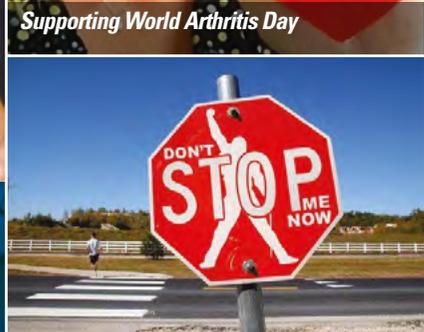
You don’t have to stop, you don’t have to give in!
Dana Berga



“Valmiera” mixed choir at their Christmas concert



Picking herbal flowers for tea



My life with lupus... “Don’t stop me now”

I’m Claudine and I am 42 years “young”. I was born and raised in Ostend, a beautiful city on the Belgian coast. I’m married to Ralph and I’m the proud mother of Lennaert (16) and Lisa (14).

I love writing and travelling, have a passion for music, wine, study and good food. I am an optimist who enjoys the “little” things in life.

I learnt about the Edgar Stene Prize through ReumaNet, our Flemish patient association. I wanted to participate because I think that “sharing is caring”. I hope that my essay can inspire others to take back control over their lives – enjoy the little things, be grateful for the things we can do and live our lives to the fullest even with a rheumatic or musculoskeletal disease... Because we are so much more than patients.

“What did you do last night?” I ask myself as my alarm clock went off in the morning. And to clarify, I had done nothing special during that night.

But, like every morning, I wake up with the headache, the flu-like feeling and the rigidity of my body. “The usual stuff”, as I always tell my husband when he asks me how I am. But this time it felt as if I had run a marathon. Which I hadn’t.

I knew this was coming. My wolf had warned me with his subtle signals.

“You’re going too far, you are ignoring me too much,” he admonishes me with his finger in the air. And I know, I realise it. But it remains so attractive to be able to keep up with everyone. Without being stopped, without being slowed down.

“Everything happens slowly”

After a few minutes, I pull myself out of bed. Everything happens very slowly. I find it difficult to think, to move and to breathe. “I’ll have to be patient with myself today,” I mumble quietly.

In the distance I hear the voice of my son Lenny. He is waiting for me at the end of the staircase with his arms wide open. I feel so blessed. His big hug creates the first miracle today.

“A big smile appears on my face”

At our breakfast table I close my eyes while I enjoy the scent of my coffee. Hmm... this is another blissful moment. And a big smile appears on my face because the sandwiches I’m making with sprinkles will taste so good with my coffee.

My mobile beeps and, in a blink of an eye, my face brightens up. It is a text message from my daughter Lisa. She is on a school trip this week. Her message makes me laugh. I miss her terribly! I can’t wait to see her again and to close her in my arms.

In the background I hear the song “Don’t stop me now” by Queen, with the ever-inspiring Freddie Mercury. They are still one of my favourite bands. I turn up the volume of the radio because it’s a great song – it’s exciting and it makes me incredibly happy! Really, you can’t stand still on that song can you? And

the small dance movements that I'm making also do virtue to the stiffness of my body.

I sing along with the song:

"Don't stop me now..."

"I'm having such a good time, good time..."

"Uh, good time?" I think to myself. No, not really no.

However I'm singing all the air out of my lungs.

Absurd, isn't it?

You know, in my mind I'm not sick. On the contrary... In my mind I'm unstoppable.

I read once in a newspaper: "Look more to your talents and less to your limitations." That's wisely said. Often we focus too much on the things that we can't do and it inhibits us. Mostly it's our thinking that limits us.

"I feel this fire inside me"

Although my lupus is still quite active, I feel this fire inside me that can't be diminished. So I had to find something that I could do with my talents and within my limits. Something that made me feel useful again. Something that I could do at my own pace.

A couple of years ago I started writing about my invisible illness and I share it in

my blog <http://wolfandthecity.blogspot.be>. It creates more awareness and more understanding about living with arthritis, living with lupus. And the most beautiful thing about sharing these little parts of me is that I'm also helping and supporting other patients. And this still gives me a lot of warmth in my heart.

"United we are changing the world"

And that feeling of helping others through my experience as a patient gave me the impulse to do more. So I now engage myself as a patient-partner and as a patient representative. I'm so happy that I can contribute and speak up for those who are temporarily unable to. I can hardly describe in words the powerful energy when we are working together in a patient panel or at a convention, putting our hands, our thoughts and our energy together. United we are changing the world into a better place for patients with arthritis. It gives me so much mental energy and friendship in return.

There was a time when I had the tendency to postpone the things I wanted to do because of my illness. But now I just do them! So I'm learning to play the piano and I love it. It stimulates my brain again. And recently I got into yoga. It helps me to regain strength. And during drama classes I'm learning to express myself again. All this makes me feel so alive again.

"Every day I scan my limits"

You know, I am aware of my sick body. I am aware of my "limitations". Every morning I get up with my wolf fur. And every day I scan my limits. What I can do and what not. What will work today and what will not.

It is what it is...

But, besides being ill and having daily pain, I also experience very beautiful, intense moments of happiness. Even if they are only fractions, a few hours, it doesn't matter. I'm especially grateful that I experience them. My focus is on the things I can do, not on what I can't. And even though my wolf often challenges me in all my enthusiasm and, even if I follow my path with much trial and error, it will certainly not stop me following my heart and doing the things I'm passionate about. It will certainly not stop me being intensely happy too.

Don't stop me now...

You are right Freddie.

The show must go on!

That's the spirit ;-).

My blog <http://wolfandthecity.blogspot.be>



Networking during a convention

My life with lupus... "Don't stop me now" Claudine Goyens



Sharing my story for World Arthritis Day 2016



Souzi Makri
Cyprus



AGORA Conference 2015 in Heraklion, Crete



With my husband Nicolas during the 2015 EULAR Congress Gala Dinner

Enjoying life to the fullest

My name is Souzi Makri and I come from Cyprus. I live in Limassol and have two daughters – Simone who is 29 and a professional freelance translator, and Konstantina who is 20 and currently studying law in the UK.

I have been part of the volunteers' force of CYPLAR, the Cyprus League Against Rheumatism, for seven years and I have participated in this essay competition before. I enjoy writing very much and my first book was published in May 2014. It is a book about my experience with rheumatic disease – acceptance, feelings and actions. In June 2015, I published my second book under the title "Moments of Life".

According to the world view of the Epicureans (ancient Greek philosophers), a happy life is achieved when one is relieved of the fears and painful thoughts which cause mental and physical suffering. Bliss equals mental tranquillity (equanimity). So, according to the traditional saying, happiness is an internal affair!

That's what I was thinking as I left the doctor's after being diagnosed with a rheumatic disease. In practice, though, it was not that easy for me to stay mentally calm after what I had just discovered.

My whole life flashed before me and in the end I concluded that those days were over. I would now have a miserable life, I would only have the memories of the good old times to keep me going.

After taking a few days to reorganise my thoughts, and visiting a friend who has been in a wheelchair since the age of 35 (she suffers from multiple sclerosis), I began to see things differently. I saw a fighter, a warrior of light who didn't give up, and that gave me strength! Life is a marathon and I would become a runner!

"Life is a marathon and I would become a runner!"

How do I enjoy life to the fullest? I taste everything with all my senses, consciously, from the moment I get up in the morning. I give myself the time I need to overcome the morning stiffness. I always used to rush to get my various errands done before leaving for work, but I never do that anymore now. My first coffee of the day smells delicious, and to me it has a completely new taste as I now enjoy it with some warm toast and fig jam!

I stare into space and I feel grateful. I thank God that I have one more day ahead of me... That I got out of bed walking, that I am healthy and full of energy, ready to deal with whatever comes my way during the day with a smile and in good spirits.

I used to forget that the sky is blue, that the sea is captivating and inviting. Even though I used to drive along beside it, I was unable to see it, I never heard it “calling” to me with its rolling motion. I see it differently now. I focus on everything I have rather than what I do not have. This gives me limitless strength to go on, particularly when I consider that there are people killing each other for a plate of food, that every day there are children dying on our planet, reduced to skin and bone and exhausted by deprivation and hunger!

“This gives me limitless strength”

I consider myself lucky to be living near the sea. I like swimming when the waters are warm and calm. I love listening to its quiet song and feeling its gentle touch on my body. I enjoy swimming at dusk when the sun is setting and I relax in the blue – this helps me have a calm night! I enjoy walking by the sea, even in winter when it’s throwing up spume and all it wants is to hurl itself in a fury at the land to rid it of anything bad and ugly. Isn’t all this a blessing?

I am involved in volunteer work and it is a perfect opportunity for me both to offer my help and, in return, to be given infinite love and more besides. Through my volunteer work, I have learned a great deal about topics that are of particular interest to me. This has helped me evolve as a human being and has motivated me to get

involved with things that have made me more creative and active, such as reading and writing.

“I have learned a great deal”

I take exercise in the swimming pool every day, and it has become a necessity for me! Under the guidance of a trainer, I do specific exercises and stretches to help my mobility, to make my joints flexible, and to strengthen my muscles. Some days when I am not feeling very well the class is adjusted to a slower pace so that I can keep up.

One of the things I love is travelling and I do not let my rheumatic disease take that away from me. Journeys are now a different colour for me, they taste different and there are many hidden beauties in them. These can only be detected and distinguished by an “eye” which becomes a careful “observer” of life and which loves the new and appreciates creativity.

“I am more relaxed”

To be able to cope with the fatigue of my travels, I plan the various things I have to do in advance. This means that I am more relaxed two days before and two days after my travels – this helps me keep my energy levels high. I always make an advance note of the things I will need to take with me. This makes for better planning and reduces my stress and anxiety levels.

Spending time with friends is something I really love. My husband and I often meet up with friends for dinner – be that at someone’s house, somewhere by the sea, or in one of our city’s squares where you sense people’s “soul” and the “beating heart” of the world! Now that our children are grown up, my husband and I have more time to do the things we couldn’t do before because of the children and various other commitments.

“I do things at my own pace”

Living with the disease does not prevent me from doing all the things I have described above. I do things at my own pace and I give myself time to rest whenever the feeling of “tiredness” which goes with my rheumatic disease becomes insistent! Whenever necessary, whenever I feel I have overdone it, I do not hesitate to cancel an outing or an event. I always wear comfortable shoes to go out and, when I am unable to walk, we simply opt for places where we can park nearby.

I enjoy everything I have described above in a completely mindful way, as I have adapted my way of thinking and my behaviour so that my life can “go on” within my personal limits. My disease has taught me what the Greek philosophers very wisely said, which is what I mentioned at the beginning: If we manage to remain mentally calm, whatever happens to us, and even though things don’t always go the way

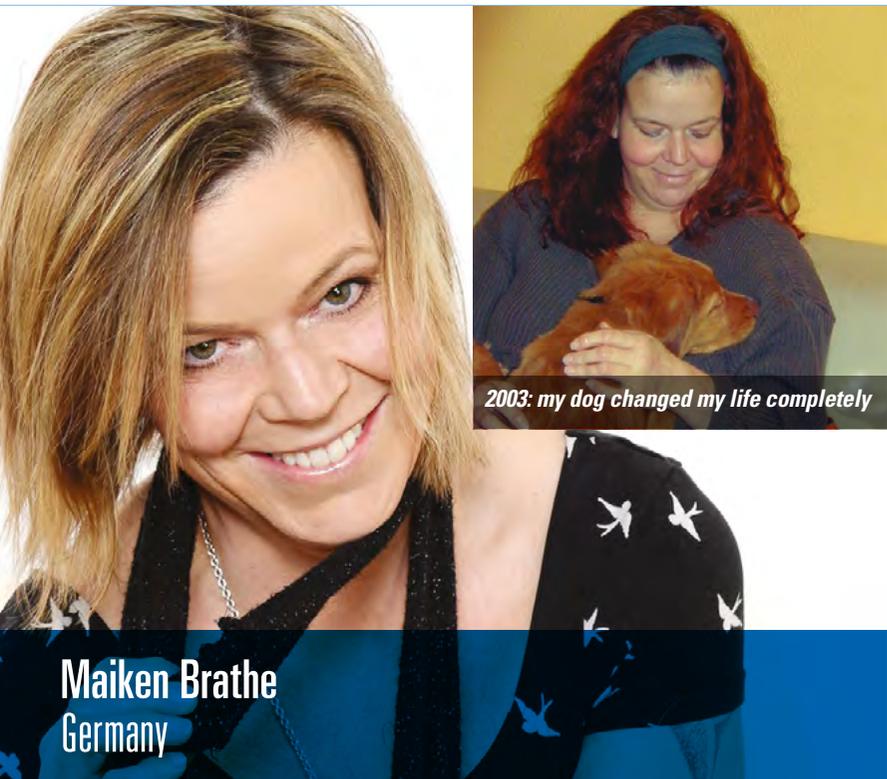
we were expecting, we can still be happy. Happiness comes, purely and simply, from within. For me, this is what gives us the motivation to live a full life, even with a chronic disease!



With friends and colleagues attending a conference in Frankfurt last spring

Enjoying life to the fullest
Souzi Makri





Maiken Brathe
Germany



2003: my dog changed my life completely



Special bond: thanks to Liv I lost more than 30 kilos and my sadness

“Skønne Liv” — my beautiful life with rheumatism

My name is Maiken Brathe and I come from Elmshorn, near Hamburg in northern Germany. I am a 45-year-old author. I am not married but I have been in a relationship for 20 years.

I have had polyarthritis in all my joints since 1980 when I was 10 years old. I am severely disabled by the disease.

I became aware of the Edgar Stene Prize through the magazine “mobil” published by the German Rheumatism League. My motivation for taking part in the competition was mainly due to the life-affirming subject. It made me want to tell others how I regained my vitality and mobility. I hope that my essay might prompt other sick people to start “enjoying life”.

“Considering that Maiken has such severe rheumatism, she does it quite well.” A sentence I have been hearing for 35 years. And what do I do well? I am simply being myself? I first learnt that through Liv. It was the 1980s when my age first went into double digits and my body suffered its first attack of rheumatism.

Whereas clinics celebrated me as an “interesting case”, I was regarded at school as a crippled special case. Orthopaedic boots brought me ridicule and spiteful classmates set me apart. In the boarding school I attended – and it had to be one specialising in sports and music! – I was the only disabled pupil. My performance did not produce a competition trophy as was the case with other children, but I did have the exotic status of a rheumatic child.

I was able to pass the school leaving examination because of a special dispensation and I obtained a place at

university because I was a hardship case. Not everyone thought that was fair. “Having rheumatism was a lucky break”. This was something I often heard.

In all the external assessments of me as a person, there was always one aspect that stood out: and that was always what I COULDN'T do because of my rheumatism!

I began to lose myself and asked myself senseless questions like “where I would be in life without rheumatism?” I felt that I was dependent on other people and, sadly, that was quite true.

“I no longer saw myself as a proper human being”

Walking became impossible and, even if new hips promised a new freedom of movement, I no longer saw myself as a proper human being – only as a lump of matter with rheumatism. If you always get told as a child that you cannot do something, then it's hard not to believe this when you are an adult. I felt as if I was a supplicant with regard to my loved ones, my parents, the authorities, the university, friends and strangers in the most mundane everyday situations.

Maiken as a mass of rheumatism felt she was invisible and alienated. I was unhappy and fat and, ultimately, weighed over 100 kg – harmful if you have rheumatoid arthritis in all your joints.

And then Liv came along, which gave me the opportunity to witness a being full of vitality on four paws and a sense of happiness for me in amber eyes that trusted me entirely.

With my dog, I began to experience the world from her perspective. Journeys were no longer just unbearable paths of pain from A to B, but contained exciting secrets to be discovered! Behind every tuft of grass there lurked an adventure!

Seeing things through her enthusiastic puppy dog eyes, I realised what a wonderful sight a boisterous bumble bee must be! I learned to hear the delicate sounds on a foggy autumn day and began to perceive how keenly a forest smells in the rain.

Now, when my crooked hands were being stared at, it wasn't because my movements were awkward but because those eyes believed these rheumatic paws would soon conjure up a dog biscuit out of the pocket.

"It's an incredibly rich gift"

I no longer regarded my clunky orthopaedic boots as hostile traitors that cried out into the world: "These feet can't move without me!" Instead, they were my allies, worn by me with pride. After all, they helped me and Liv to find new adventures every day.

But, most of all, I realised what an incredibly rich gift it is to care for a creature that loves me unconditionally.

From that moment it was as if someone had taken the dark glasses called disease off my nose and had magically coloured the world for me. Seeing myself through the eyes of my dog showed me another reflection of myself which was not what society reflected to me.

"Every uphill struggle was within my grasp"

I actually saw myself – the loving Maiken, the fighting Maiken, the caring Maiken who is a warrior when it comes to protecting my loved ones. Liv knew nothing of rheumatism, made no special allowances or gave me any special treatment as a patient (unless it was special treatment in the form of an extra sausage for dogs to eat). For her, my fingers were not crooked and my gait was not strange. Her assessment of me resulted from her uncompromising faith in me and the conviction that I would do anything on earth – whether it was "eliminate the snarling curs for me" or "make the North Sea at low tide come back again".

I started to emerge from my identity as a mass of rheumatic matter, lost 35kg of body weight and gained immensely in mobility. Social contacts and skills grew, as well as the routes that I could travel more and more each day. Defensive Maiken became a self-confident woman.

The forecasts that I would have to sit permanently in a wheelchair lost their

terror for me, and their credibility, with every metre that I managed to walk every day. Of course at times I was also overwhelmed and doubted myself – as did the healthy people around me. However, if you are responsible for someone else, you cannot let yourself go. You get up, even if it seems impossible, because the being that trusts you should not have to bear the consequences of your own weakness.

Because of the boundless confidence in me, every monumental uphill struggle seemed to be within my grasp, even if the one rock I am pushing uphill starts another rolling. Given the responsibility that I have, there is no way back and so I find a different solution.

That does not necessarily mean that I mastered everything physically myself. I am learning to organise help for myself so that I don't give up in advance, and I don't let myself become alienated and passive like I used to be.

Detaching myself from my former persona under the domination of sickness progressed like a line of dominoes – one after the other was knocked over by my altered self-perception, creating a wave-like forward motion. But I did not fall over like a domino, whereas my resignation and my phlegmatic self-image did indeed take a tumble. I managed the impossible – things which, emotionally, were barely endurable and which I never thought I would be able to manage as a handicapped woman. I finished my exam, although a brain infection had not yet healed. I accompanied my mother with

love and care until her death from cancer and wrote a book.

"It was a liberating feeling"

And all this was possible because, despite doubting voices around me, I decided as a severely handicapped woman to take responsibility for a fun-loving dog. The censoring voice in my head telling me I could not do something was no longer there. My strategy was an unconscious one. It was a liberating feeling, drawing attention away from rheumatism and directing it towards something lovely.

In my case, it was the dog. For others, perhaps it's motherhood, a job, a social task that requires regularity, but also promises feedback that nothing – absolutely nothing – has anything to do with rheumatism!

Getting out of bed despite pain, doing something, pulling yourself together, welcoming the day and concentrating on what is beautiful. That is what my life with the dog has taught me. For Liv, I was Superwoman and, through her, I also began to feel that way. Now I know what I can do – irrespective of the rheumatism.

And for Liv I found the strength to return to her all the love that I learned to experience through her. Until her last breath in my arms.

My dog was called "Skønne Liv". That is Danish and means "Beautiful Life".

My life is beautiful. That is my aim and I have achieved it – despite the severe rheumatism in all my joints for 35 years.



2002: the illness made me sad and fat

"Skønne Liv" – my beautiful life with rheumatism Maiken Brathe



2014: my beloved "personal trainer" passed away. I owe her a new active life



Rita Gruber
Hungary

Bike tour with my friends



On top of the world. We succeeded!

Living a full life

I am Rita Gruber and I am 34 years old. I was a hairdresser by profession, but now I am a high school student. Nowadays I live in Budapest with my friend. I am lonely – I have lost my family members.

I regularly visit the website www.bechterewes.hu which is the website of the Hungarian Bechterew Association and is where I got the information about the competition. I wrote my essay because it is good to tell that there is always a way out of problems.

My father died eight years ago, he was a cancer patient, and I lost my mother in September, she had an orphan autoimmune disease. I kept her company to the end. Writing about my life helps me, I am still here, life counts with me and I count with life.

I live with a locomotor (rheumatological) disorder. How do I try to lead a full, enjoyable life with it? The symptoms started when I was an adolescent, but I didn't see a doctor for a long time because I really didn't think it was anything serious. The first thing was that I had inflammation of the iris while I was at secondary school. My family couldn't understand it. I underwent treatment, and it went just as it had come. We soon got over it.

I must have been 16 or 17 when I had shooting pains in my waist that kept coming back. We all thought I was growing. The problems were mild to begin with, and they soon passed. Later on these phases became longer, but they were interrupted when I took more regular exercise, which somehow prevented them.

I reached a point where I couldn't fail to notice that something wasn't right with me. That was when I went to an orthopaedist for the first time, who immediately referred me to a rheumatologist. That was followed by tests, and then waiting. It is not a time that I remember with fondness.

"I wasn't going to settle for that"

I have known that I "suffer" from Bechterew's disease since I was 22. I say "suffer" in quotation marks because I cannot live with the idea that I am suffering in some way, or that I have been struck down by something. I would prefer to say that I live with it. It has been a long journey up to this point. Twelve years have passed since my diagnosis, and I have gone through various phases since then, both mentally and physically.

I will never forget the day when the doctor told me what my illness was. My first question was "what could I expect in relation to my future?". I was given a short answer – too short for such a serious question. It was only five words: "I'm not a fortune teller". I have always

been stubborn, and I wasn't going to settle for that. I consulted several doctors, believing that there had been some kind of misunderstanding and that they were all wrong. It's clear now that they were right.

I wanted to know about the future, and always asked what I should prepare myself for. I remember the feeling when the dreams I had woven for my life were suddenly pulled out from under my feet. Then there were the treatments, the medicines, and the days and weeks spent in hospital. There was no significant change in my condition and, when I was 23 or 24, I was pensioned off and had to give up my career. The huge amount of free time that I had was a burden, and aimless thoughts ran around inside my head. I let myself sink into self-pity. I was in pain.

“I felt I was living in a prison”

During the most difficult phase, my mother helped me put my socks and shoes on. The space around me became more confined and I felt I was living in a prison. I felt I had no prospects and that my life had no meaning. I was discontented and fought against the circumstances. Maybe I'd had enough of myself because, ultimately, I was overcome by something else: the desire to live. A sense of obstinacy and instinctive resistance was aroused in me; I wasn't going to end my days not having even tried. I sought some meaning, a way to move forward... Something to give me a goal.

That's when I saw the advert for a hospice, which was looking for volunteers. I don't know what made me go to them. Back then, I was afraid of everyone and everything, but I still got over myself and went for the interview. I underwent training, as part of which we were treated by a psychologist and performed various exercises as a group. I went so that my existence would have some meaning, so that I could help.

“I didn't want to upset my family”

In the meantime, the thing I had least expected happened. I slowly got better. I was finally able to speak freely about my disease at the preparatory classes. I didn't dare to be honest at home, because I didn't want to upset my family. But in the group, and in front of the expert, I could. As the other members of the group were also affected by some kind of health problem, we could share our experiences. Some of them were recovering from cancer.

At one of the classes, we were given the task of drawing a picture of what sickness meant to us. I drew prison bars. I thought that sickness always closed everyone in. To my very great surprise, an older lady drew a flower. I didn't understand. I could not have understood then. During my volunteering, I spoke to people who had tumours, and those conversations made a deep impression on me. One afternoon, I was sitting on the bus home. It was still cold, but the sun was shining in through the window.

I turned towards the light, and smiled. For the first time in a very, very long time, I felt that life was good, despite everything, that I was lucky. That was when I realised that “I have been struck down by a disease” had changed into “There's a condition that I live with”. I live with it, but not in it.

The people around me, who had lived their lives through great suffering because of their tumorous diseases, had shown me that I should love life and love the days that I have – the days that I have right now. Of course it isn't that easy to do, but my attitude has changed. Loving life has become my philosophy for living. I have learned to dance, even though participating in the classes was different for me than for the others. I felt my boundaries, but I was there all the same. I loved running, but now I can't. Despite this, I ran a relay marathon three years ago. I was very slow and our team came last, but it didn't bother me in the slightest. Years before that, I had wondered how I would ever get up after sitting down, so in comparison with that it was a victory in itself.

“Loving life has become my philosophy”

I can honestly say that I have now managed to do everything that I've been drawn to. Bechterew's disease has not imprisoned me, but has given me opportunities. That's why I've been throwing myself into things for several years – to prove to myself that I'm capable of doing them. Everything I do

now stems from the self-awareness I have gained from my many experiences, and I can thank my condition for that. But the pain that rears its head again and again does not let me forget that I have a “companion” on this journey and, at the same time, it reminds me how much strength I am capable of mobilising if necessary.

I don't know what tomorrow will bring. I don't ask anyone anymore because doctors represent science, which definitely cannot give an answer for everything and it does not tell anyone's fortune. I don't either. I don't guess, I don't look very far ahead; I just pay attention to the bends in the road that I can see. I do look back from time to time, but only to remind myself where I started from.

I'm 34 years old. I'm in my first year of college. I don't have children and I'm not married. I am a woman who is living a full life. And I happen to have Bechterew's disease.



Living a full life
Rita Gruber



With my mother

Sight-seeing, and visiting museums and exhibitions help me feel in touch with life



Friends are crucial for my inner balance



Laughter is a great medicine for body and soul

Maria José Rosado Balão de Castro Portugal

A step ahead of the disease

My name is Maria José Rosado Balão de Castro. I am 55 years old and married. I was born in Estremoz and I work as a secondary school biology and geology teacher.

I first heard about the Edgar Stene Prize some years ago through the magazine of the Portuguese League Against Rheumatic Diseases.

I write in my leisure time and use it as an activity to calm me, reflecting and purging less positive feelings that sometimes overwhelm my mind. I decided to participate because it is my way of repaying the League a little for all it gives me. Moreover, I will always do everything I can to help disseminate information about rheumatic diseases. They are so aggressive to their sufferers, but still so little is known by society in general.

Fibromyalgia is a cynical, persistent and downright annoying disease. It appears, sets in and is always with us – in the light of day or in the darkness of night – bothering us whenever it wants, without caring if the time is right and without the slightest concern for convenience. It is true that, if it were not so shameless as to impose its presence, it would never be invited as no one likes it. Silently, it attacks the muscles or the brain with neither ceremony nor parsimony.

However, despite this insolence, it never shows itself nor publicises its arrival. It just appears secretly and irreverently.

We do not know where it began, why it began or when (and where) it will deliver its next blow. We know neither its form nor its modus operandi. And so, surreptitiously, it takes over our body with the security of the unreachable.

At some point it becomes a part of us, like a feeling – malevolent, something very intimate that we can describe or assign a value to on an unreliable scale, and externalise in expressions of pain or unhappiness. But we will never really be able to show it to others. It cannot be photographed nor detected using some lab test. Now this, at a time when the Exact Sciences dominate our minds, is bad for the person suffering from this syndrome.

If our enemy does not show itself, how can we expose and eradicate it? If we are not familiar with its actions, what is the best strategy to fight it?

These were the questions that tormented me in the beginning on those frequent sleepless nights or during forced breaks right in the middle of my daily routine – or imposed downtime lasting several days.

And the same, increasingly clear, answer always began to form: to prepare myself for the attack as best I could and strike quicker than the disease. I had always heard that the best form of defence is attack.

So establishing rules was one step. By no means was this a short step but, nevertheless, it was a step in the right direction. I started by assessing how it attacked me and I soon realised that my weaknesses were the disease's strongest times. My brain plays on two teams and takes advantage of my weaknesses, serving them up on a platter for fibromyalgia to use them to score points to bring me down.

So, I thought, I must always be one step ahead of this wily disease. By ascertaining my moments of greatest physical or emotional weakness, I can take steps to prevent the incapacitating symptoms from setting in.

And so the golden rules started to emerge: essential for balance in my life.

**Rule number 1:
Together with my doctor, work to make our team very strong**

- Discover the right drugs to protect and strengthen my body's weaknesses. He searches and I test until we come up with the ideal formula.
- Comply scrupulously with his orders, and follow his advice with the utmost seriousness.

**Rule number 2:
Coax my brain to be on my side instead of letting it freely choose which team to support**

- Occupy and exercise my mind so that it is not led to wander into the meanderings of depression so appreciated by the disease.
- Use the disease as an argument to dedicate myself to tasks that give me pleasure – loved by my neurones, impelling them to participate – but which used to be relegated into second or third place due to a lack of time.

**Rule number 3:
Prepare my body for the almost always unexpected attacks**

- Strengthen my muscles via appropriate exercises to make them more resistant to the malicious attempts to make them stiff and sore.

**Rule number 4:
Never give up**

- Do not stop doing anything, whatever it may be, because of the disease. Rather, persevere and adapt to achieve my goals.
- Especially, NEVER use the "I can't do that any more" argument in order to avoid an activity. Face it, study it and achieve it – even if it's only 10% of what it was supposed to be.
- Foresee situations that are most susceptible to crises and prepare my defence.

**Rule number 5:
Use good humour as an indispensable ally**

- Disparage the disease in the day to day by preventing it from becoming the centre of attention and thus gain ground.
- Play with it more than it plays with me, counteracting the dramatic trend it establishes in the games it plays with my body.
- Surround myself with family, friends, good workmates and people who make me laugh, feeling that I am part of a large community instead of making myself an easy target by isolating myself.
- Laugh every day, taking laughter as food for the soul.

**Rule number 6:
Whenever possible, avoid situations that cause stress, negative ideas and depression**

- Avoid disputes, arguments, and confusing and noisy environments at all cost.
- Keep away from negative people, pessimists for whom things never have a solution.
- Prefer healthy, humorous books and films or ones that propose solutions to problems from a pro-active perspective.
- Allow the sad events from which I can escape – because my participation is not required – to take their course, without involving myself.

I am not sure if I always follow all of my rules, but I don't think so. Sincerely? I am sure I do not! Why? Because sometimes I despair, other times I cry and others I even drown in self-pity. But immediately afterwards, I avoid reproaching myself and I think that I am human and have the right to make mistakes. And I believe, above all, that rules are there to guide us and lead us along a path, but that it is the exception that confirms the rule. Therefore, we should live and accept our rheumatic or musculoskeletal diseases, as (undesirable, I know only too well) inseparable companions.



A step ahead of the disease Maria José Rosado Balão de Castro



My cats are great company at all times



Darina Kostíková
Slovakia



With my dance group "Gold"



Performing with "Gold"



High5 in High Tatras

Never be afraid to dream

My name is Darina Kostíková and I am a kindergarten teacher living in Bardejov, Slovakia. I am 53 and married with three children and two grandchildren.

I have been volunteering at the Slovak League Against Rheumatism for three years and am informed of everything that is taking place at the European level. It was through them that I heard about this competition.

I decided to participate because this topic was very interesting for me. I wanted to share my fortune with the readers despite having suffered with a rheumatic and musculoskeletal disease for 30 years.

I had long felt that my life was hard and demanding. When I now compare myself with friends with rheumatism, I see that it was much easier than theirs.

Life has dealt me a few blows: psoriasis, visual impairment, miscarriage, premature birth of twins at 34 weeks, rheumatism and, finally, a diagnosis of practical blindness. I don't even properly know what this last one means, and for peace of mind I won't try to find out. These entries in my medical record are quite enough for me.

When I was six, I was diagnosed with psoriasis and, along with it, amblyopia. Both diseases affected my self-confidence. I grew up in a village where everyone knew everything about each other, so I felt that people were pointing at me. Red, scaly patches all over my body are not particularly nice to look at. On top of that, I wore glasses and an eye patch. I suffered greatly and I was ashamed of my appearance.

The word "psoriasis" was still taboo a few years ago. People didn't know it. No one wanted to talk about it in public. Since childhood, I would ask "Why me?" I played second fiddle to my classmates and friends – maybe even third. I disliked being with children. I preferred to stay at home reading, and I would only play with my siblings.

"Suddenly I wanted to live again"

Long-term therapy and a variety of treatments finally brought success. The scales on my body disappeared and remained only on my scalp. It was a miracle. Suddenly I wanted to live again, to meet up with friends. My self-confidence gradually returned. This was how I lived for several years, until a further diagnosis added something to my varied life: rheumatism.

I was 24 years old and had my whole life ahead of me. My joints started to feel painful. I had been happily married for three years, and my husband and I were planning to start a family. The first time it didn't work out. I lost the baby at three months.

Three years later our faces were once again brightened with a smile — we were expecting twins. Tears of joy and happiness followed. The euphoria only lasted until the third month. I got chickenpox. It was not pleasant, with itchy rashes and temperatures in the 40s, and among other things, the possibility of foetal harm. I was terrified. But the worst was the uncertainty and fears.

Fortunately, our guardian angels were looking down on us and the children were born healthy, if about six weeks premature. After the twins were born (weighing 1.75 kg and 1.50 kg), I blamed the fact that I had no time to myself, that I was all tiredness, exhaustion and joint pains, on caring for the babies. It was only after my second pregnancy and the birth of my third daughter, when the pains did not pass and my fatigue was getting worse, that I was diagnosed with rheumatism, specifically psoriatic arthritis.

Twenty-seven years have passed since then, but I remember it all very well. The first treatment was unsuccessful. The drugs that eased the rheumatic pain brought about and worsened the psoriasis. So, at the age of 26, and with three small children, I was back at square one. Psoriasis erupted all over my body. The rheumatic pains were a bonus! Aching, tired, weak, and now ugly to boot.

You might not believe me, but because I work as a teacher in a nursery school

where I come across fairy tales every day, I have dreamt up my own fairy tale. It is called “Happy RheuMummy”. I don’t plan my life, I take what comes along. And my 50th came along and, with it, a sudden change in my life. At last I had time for myself and my hobbies.

We all have our own view of the world, and the word “happiness” means different things to different people. For me, happiness – and the most important thing in life – is the fact that my husband and I have managed to raise three healthy and successful daughters.

“Happiness means different things to different people”

But now that the children are independent I have found a new hobby, and that is volunteering at the Slovak League Against Rheumatism. It gives me pleasure and brings into my life new experiences and new friendships with patients with rheumatic and musculoskeletal diseases (RMDs).

The League pushes me forward and gives me new strength to face life. I have met many great people there who are like family to me. At the League I also found a real friend, whom I would not trade for any gemstone in the world. She showed me how to move forward and not always see the faults in yourself, but also the goodness and beauty. She taught me to think positively. Thanks to her, I started to

feel successful and self-confident.

Perhaps this is one reason why this year, at the age of 53, I decided to fulfil a dream. I have enrolled at a private art school and have taken up modern street dancing. Our group of 15 young women – mothers whose children attend this school – is trained by our skilful teacher. Thanks to the dance group, I am once again part of life. Dancing is, for me, adrenalin, endorphins and joy all in one. After hours of training, when the pain in my legs becomes severe, I might have a little cry and sob into a pillow. I tell myself that I will quit, that there will be no “next time”. I am worried that I won’t be able to go on, that it won’t be possible. But when it’s time to train, I do not hesitate even for a second and I launch myself into it again.

In November, we took part in a Slovak dance competition, MOVE ON! Dance Cup in Žilina, where we won a magnificent first place in our category of seniors over 25 years of age. We participate in various public appearances. The dance school has a great team which takes me as an equal partner. They support me in my dancing and cheer me on. They don’t want me to stop dancing: age is just a number, apparently. I will never forget the trainer’s words when he said “Daja, I take my hat off to you. You dance your own way, but with such skill that everyone thinks this is how it should be.”

Nothing can motivate me more than these words. Since then, I have been dancing with even greater passion and joy. I cannot get enough of dancing because it was something I denied myself for years. I feel great when I am with the dancers.

“Nothing can motivate me more”

I am also supported in my dancing by my nearest and dearest — my husband, three daughters and two granddaughters. They came to cheer me on and encourage me with their applause at the dance competition in Žilina. So what if I can’t open a jar of pickles or an ordinary bag of pasta with my hands?

For me it is my legs that are now important, for it is my legs that must master the dance moves. Many people really do envy me.

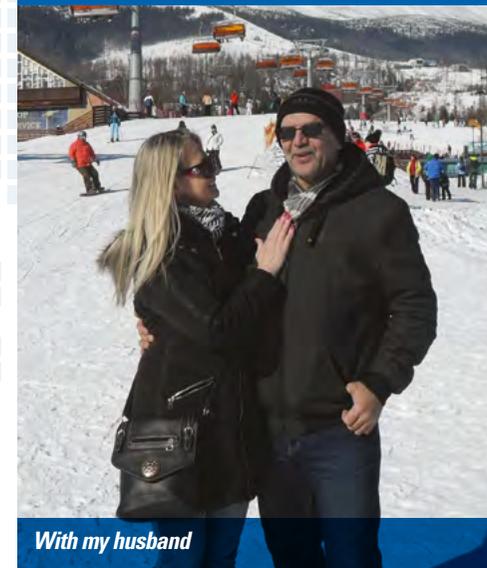
This, for me, is real happiness and a full life. I know that everyone has different ideas. For me, happiness is my parents, my children and my hobbies and, therefore, my rheumatic friends and my most beloved activity at present— modern dancing in the group “Gold”.

I live life to the full, even though I have rheumatism. One must never give up without a fight. One must move on and try new things. What if fortune smiles again? Dreams come true only to those who are not afraid to dream. Mine have now come true.



Family vacation in Croatia

Never be afraid to dream
Darina Kostíková



With my husband



Maria Pilar Pazos Casal
Spain



Relaxing with my husband Tino, and our dogs Bilbo and Troylo

The key to enjoying life

My name is Maria Pilar Pazos Casal and I am 54 years old. I live in Ferrol ((La Coruña), Spain. I was a teacher by profession but I am now retired due to absolute and permanent disability.

I heard the call to enter the Stene Prize competition through the Spanish Federation of Lupus (FELUPUS). I decided to participate because, ever since I was diagnosed with my illness, I knew I faced a new stage in my life. I have wanted to dedicate my life to helping others and believe that my story can be an example of that. Although it takes a lot of courage, I know that you can live with a chronic illness without losing your smile.

I have always been an “oak” without even realising it. Maybe when fate “heard” me crying for the first time, it became obvious that my life was not going to be rosy and I was given the gift of strength.

In the autumn of 1984 I discovered lupus, with its fears and anxieties, with its heart-breaking future image. I did not want to turn into a weeping willow; this strength I had inside me anchored to the life I would now begin to “live” with strong roots. My body suffered... I cried for my parents, for my love, but there was no point feeling sorry for myself, there was no point asking questions... My roots clung on and there were others helping me, holding onto my branches, caressing me with their leaves... and so I began to learn to live with my lupus.

Having a disease is hard – we all know the everyday details of that. But even if you have a disease, there is no need to feel ill. That’s the key to enjoying life,

making sure “normality” takes over everything. In the end, we are able to follow our life’s path, knowing our body, listening to our heartbeats, learning about our illness and letting life go on each morning.

La importancia del roble va mucho más allá que la utilidad de su madera... Para todos los pueblos que lo han conocido constituye un sinónimo de fuerza, de no dejarse doblegar ante ningún obstáculo. (The importance of the oak tree goes far beyond the value of its wood... For all the people who have come to know it, it is synonymous with strength, not letting oneself be defeated by any obstacle.) Miguel Herrero Uceda, El alma de los árboles

“I began to live my life”

So with that strength, I began to live my life. Living your life with a smile makes everything simpler – easier for you and for those around you. You need to start by introducing this normality to your family and your work environment, your friends and neighbours, showing them what it is like to have a chronic disease and going through it without any dramas. That would be a good start

for a somewhat rough road, where you need to learn to be patient and to love yourself. I learnt to understand others and how to make others understand me.

And life goes by, like the seasons – either freezing cold or real spring weather, falling and rising again and again... with the help of my loved ones.

I learnt to ride a bike when I was 40! I could not believe it!!! Now I have a tricycle, but I continue to “run” without losing my smile. I had two travel companions – Bilbo and Troylo, two wonderful poodles. They made me really happy and, together with my beloved Tino, my partner, my husband, my friend, we became one happy family. These are magical moments in one’s life and they mark you for life. And I was happy.

My work was always gratifying. I taught my students so much and learnt so much from them at the same time! I remember their faces in the adult education for dependents phase. Every day was a gift, every sad story was exciting at the same time and I was happy to see adults learning to read and write.

I cannot even describe how good it feels knowing that you have helped make this possible: we read, we did maths, we drew, we told each other small and big secrets, and some even fell in love. I was feeling more and more grateful for all this. I had other

students, always adults. They were complex students with various integration issues, coming from broken homes. Each year was a challenge, a desire for them to show enthusiasm, a constant struggle for them to “like themselves, for them to be convinced that they were worth a lot, that they had a future”. I was growing up with them and I was happy to see their achievements.

“I have to get a lot more rest than friends do”

I don’t have many friends but my friends are all wonderful, they are like gold. Spending an afternoon with them is like reliving my teenage years, although I must admit that after every outing I have to get a lot more rest than they do... and I go on laughing and living.

My parents... their grief over my illness, keeping it all inside so that I would hardly notice. My father is no longer with us... My mother is always there and that makes me happy. My diagnosis aged them. It aged their body and their soul. Having them around always made me happy.

Altruism, love for others, solidarity, empathy... This was a very happy phase and it taught me a lot. It was the phase that made me a better person. 1997 was a very important year. I got involved in the fight and support by and for all people with chronic diseases – lupus in particular, which is the disease I have. And yes, I do have to be grateful for this choice of life.

I have got to know so many wonderful people. Without lupus they would not have entered my life. There’s always the bright side, “Hakuna Matata”, despite the adversity, the pain, the medication, the hours spent in hospital, the cold operating rooms, the intensive care units, despite the losses... We need to live our life, enjoy it because that’s all we have. It is just one word but it is so important. If we know how to use it with empathy it can become immense.

Prioritising. This is a word I like. Prioritising is the key to living life to the fullest. Knowing how to find the formula that allows us to feel happy with our limits, sticking to what makes us happy and getting rid of everything that bothers us. It’s not easy, nobody gave us an instruction book showing us how to do it.

“Enjoying life to the full is so relative”

Enjoying life to the full is so relative. It all depends on what we are expecting, on habits such as reading and writing, drawing, listening to music, motorbike rides or walks in the forest, the sea... emotions, smells... Everything is a gift of life, trivial things that we hardly use. Without any great aspirations we can be happy, we can be made happy. At the end of the day we need to be happy with what makes us happy, letting the disease guide us.

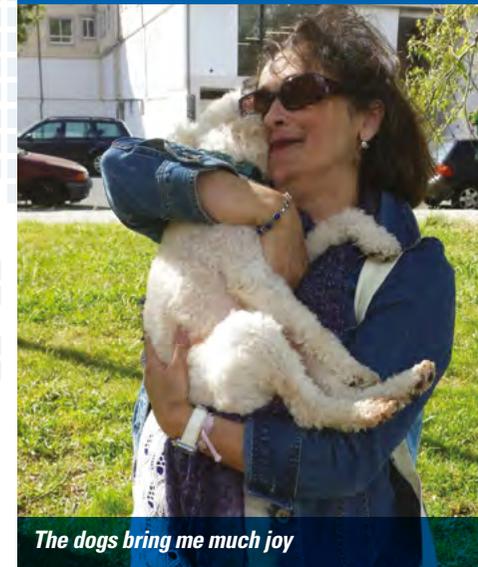
Even if we are suffering from a disease, it is the heart that should

guide our actions. We need to keep it healthy for our emotions, to be able to give and receive.

Having fun for me is giving your best self. As Voltaire would say “I have decided to be happy because it’s good for my health”. And what I like is making the most of things – enjoying every moment of my life, always with a smile, never wasting time. All of course to the extent that my body lets me do it. And I am an oak.



The key to enjoying life
Maria Pilar Pazos Casal



The dogs bring me much joy

Meet the other essayists



Ludmila Tomaskova



Charlotte Marie Ochsenbauer



Marjukka Mykkänen



Evdokia Anemogianni

Czech Republic

Ludmila Tomaskova
Klatovy, Czech Republic

Let us adults learn from the children. Let us not be slaves to our pain; let us say to ourselves that we can live life to the full. Because if you say I cannot do it, I am not well, I have no strength, I cannot cope, then the 'not' will take over your whole life and you will cease to live. You will merely be surviving.

So find your own motor, some sort of strength to guide you and turn that "not" into beautiful words – I can do it, I will try it, I feel better, I can cope, I can succeed. You will see that, despite all your pain, you can perform miracles, be happy and live life to the full.

You help someone and he, through his behaviour and actions, helps you. You feel recharged and you help someone else, and again you are repaid and you can be happy and enjoy life to the fullest.

Denmark

Charlotte Marie Ochsenbauer
Copenhagen, Denmark

For the last seven years I've had control of my life. I've organised demonstrations and I left home when I was 17. I have a lovely boyfriend and nice activist friends. I'm now working in Copenhagen and trying to see what I want to study. Some days I am in pain.

The new year begins tomorrow. I feel that I'm on the verge of a new life. I can only move forward when I've dealt with my illness and my history of illness. That's why accepting is really important. It has to be done first. Can't you just ignore the rheumatism and have a good time? It doesn't work like that though when you're going through a rough patch.

To be able to live a full life with an illness like this, you have to recognise yourself. You have to come to terms with the fact that the pain is a part of you, and that your body is sick. If you accept your illness, you look after yourself.

Finland

Marjukka Mykkänen
Savonlinna, Finland

I have never yet heard anyone say that a patient might gain from rheumatoid arthritis. Only adverse effects are ever mentioned. After all, medicine is dedicated to removing adverse effects, and a good thing too. I feel that it is only the patient who is able to effectively identify any benefits that an illness might bring. Over the years I have met all sorts of different people through a link to rheumatoid arthritis. People who brighten my life and introduce humour to it are often those with the same illness.

At the moment I enjoy a good, active life in my beautiful home town – both at work and in my free time. I will have time to sleep in peace later. In the sarcastic title of his cantata "Ich steh' mit einem Fuß im Grabe" (I stand with one foot in the grave), Bach echoes my thoughts, but the buoyant musical harmonies of the piece add a positive slant to my today and to my future.

Greece

Evdokia Anemogianni
Athens, Greece

My favourite hobby was gardening – I really needed to do something I love. And as they say, when something makes you happy, you always find ways to dedicate time to it. I always had a cushion with me in the garden. I sat down on the ground and started looking at my plants from there. I bought some small, light garden tools. I did some digging, some pruning, some cleaning, all while sitting on my favourite cushion.

Eventually I quickly realised that this was a fun and relaxing way of doing things! Down there, I became one with the garden and I was able to see details that would go unnoticed when I was standing up. The results were prettier! Of course I did have some pain in my joints, but I avoided standing as that made things worse. Furthermore, I was doing something I really enjoyed – something that improved my mood – and that had a very positive impact on the rehabilitation of my joints.

Meet the other essayists

Israel

Lizy Zommer

Ramat Hasharon, Israel

I visited my physician almost every week with the expectation that he'd define my illness. I was embarrassed every time I visited him, taking too much of his time, but I said to myself that this is not an option to stay in this condition. I needed to know what my illness was. It is only when you know what you have that you can do something to change it.

I started to help others who suffered from chronic fatigue syndrome and fibromyalgia in my new role as a counselling psychologist. I voluntarily manage support groups of patients and their families and teach them my programme and share my experience. When I get a call from patients who have recovered and have got their life back, it makes my life exciting, happy and satisfactory.

Hope, positive thinking, volunteering work, physical exercises, fulfilling your dreams and helping others is the way for enjoying life to the full with any medical condition that you might have.

Netherlands

Nurjanah Bruggeman

Leek, Netherlands

I have long felt trapped in my body and felt like a bird with its wings clipped. And yet I learnt to fly. I regularly made nosedives. My spiritual strength, love and my inner compass have always guided me to the correct destination. My passion to raise awareness about scleroderma has contributed to my life and enriched it with activities on a national and international scale. For example, the photo exhibition called Scleroderma Framed, the international documentary Project Scleroderma: Beneath the Surface and my commitment to Komunitas Scleroderma Indonesia.

With the limited energy that I have, I will always prefer my passion for life over the pain and fatigue that I experience every day. I spent a long time being unhappy but, since I started following my inner compass, I have started to love myself.

Romania

Florin Catrina

Bucharest, Romania

My secret for a happy life has been my family – how can you have a truly positive attitude if you don't have a good family environment? I decided to marry the woman who had been there for me and who had helped me to get through those awful times at the beginning of my illness. And of course she said yes.

Since then, things have got better and better. And, in 2011, the best drug of all came into the world – my little boy Horia. Recently, I realised that I am learning to walk alongside my little one, crawling, crouching on all fours and then walking on two legs. As I ran after him and went through all of the stages together with him, I was pleasantly surprised to see that I "found myself" on two legs again. I walked more easily and with less pain. Whatever sport I might try, it wouldn't compare with the process of learning to walk.

Serbia

Verica Djuric

Belgrade, Serbia

When I say that I just can't do something and my youngest son says: "Are you sure? And have you really tried, now, at this moment?", I am surprised at how often he is right. Far too often, through inertia, I say that I can't do something. And when I try, the opposite happens. I realised that I have to push the boundaries constantly, and that it strengthens my ability and, in turn, the structure of my personality.

The small steps I repeat over and over every day make the big steps towards living a full life. And I really enjoy life. We only have one life, and we need to take full advantage of the good things in life, to turn each situation to our favour so that it is not impossible. We need to make every effort, but the gain is huge. We need to raise confidence to the highest level in order to walk boldly through life – the only one we have. Let's enjoy it with our family, friends and people dear to us.



Lizy Zommer



Nurjanah Bruggeman



Florin Catrina



Verica Djuric

Meet the other essayists



Boel Löow Zambrano

Sweden

Boel Löow Zambrano

Stockholm, Sweden

My strategy for living life to the full despite poor health involves using imagination and humour – putting on an inner soundtrack when I have to tidy up, playing, inventing film titles which describe the day, giving myself different roles and challenges which have to be faced. My aim is always to be as active as possible.

I have benefited a lot from getting a diagnosis after so many years, being able to go to the pain clinic for pain rehabilitation and being listened to and understood. I've joined the Rheumatic Patients' Association and get so much out of it. I have wonderful workmates and I try to do my bit. My family supports me.

The hardest thing has actually been the demands I make on myself and accepting the new situation. The pain, the reduced stamina, the things that are difficult or virtually impossible... The whole balancing act of not doing too much on the good days... Not dropping out of the good things in life.

Switzerland

Micheline Hösli-Stettler

Châtel-St.-Denis, Switzerland

Walking and swimming are regular activities which I find helpful. Nothing heroic, obviously. I undertake any activity at my own pace knowing that, in this way, I get a good feeling for my body. Every day, I advance bravely in a heroic fashion. Some people follow the pilgrim's route to Compostella and boast about arriving at the Spanish Finisterre as victors. As for me, every day I am just pleased to have overcome the pain of fibromyalgia.

Sometimes I collapse but then I do not hesitate to have a lie down and take a good book that makes me think of something else. I stroke my 19-year-old cat and his purring soothes me and restores me. My positive thoughts take over again and I'm flying for another heroic conquest all alone.



Micheline Hösli-Stettler



Living with a rheumatic or musculoskeletal disease –

How I take action to
enjoy life to the full

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