



EDGAR STENE PRIZE 2014

**VISION 2043 — MY IDEAL WORLD
FOR PEOPLE WITH RHEUMATIC OR
MUSCULOSKELETAL DISEASES**

eular

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



The European League Against Rheumatism (EULAR) is the organisation which represents 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

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STENE PRIZE BOOKLET 2014

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A window to the future

It is a pleasure and honour to compose a Foreword addressing the readers of the 2014 Stene Prize Booklet. This is the sixth Stene Prize Booklet – the first being published in 2009. It has become one of EULAR's most valued publications today, not only within the organisation but also with policy makers and health professionals at national and European levels.

This year's topic was titled "Vision 2043 – my ideal world for people with rheumatic or musculoskeletal diseases". We have received contributions from 17 member organisations. 17 people living with a rheumatic or musculoskeletal disease (RMD) who shared their personal dreams with us and it was an insightful experience to read what matters most in the life of people with RMDs. I discovered that many visions are also dreams we share as rheumatologists and health professionals – preventing RMDs, an early diagnosis, access to treatments, finding a cure or being able to treat RMDs effectively and without side effects are of course the very reasons why we have chosen our profession.

Our visions go hand in hand and, although a lot of progress has been made in the past years, it is clear that there is so much more

to do. Reading the essays shows us, in a powerful way, what really matters to people with RMDs and what the issues are which need to be addressed most urgently.

But there is not only a role for us as rheumatologists and health professionals to make these visions come true – society as a whole is asked to shift attitudes to a society where people with chronic diseases and disabilities are fully accepted and valued.

In many countries being chronically ill is still a stigma and the need to share information and to raise awareness is high. Being able to work flexible hours, part time or from home, would offer people with RMDs opportunities to stay in their job or to find suitable work. As we can read in many essays, the ability to work is of great importance. There are a lot of barriers out there making the full participation of people with RMDs in society impossible. It is our role here as EULAR at the European level, together with the patient organisations at national level, to help society make the shift. It must offer an inclusive and accessible environment where people with chronic diseases and disabilities can equally participate.

EULAR offers a platform for all those who share this vision – for those who want to see a better quality of life for people with RMDs and enable them to live their life to the full. What we hold

in our hands with the visions for 2043 is very important – it is our agenda for future change which needs to be implemented. It is one of the engines 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 the society.

I would like to sincerely thank all those who have participated in the competition for sharing their vision of an ideal world for people with an RMD. I was very touched by being invited to witness their dreams and I was impressed by their courage, positive attitude, strength and humour to live their lives despite the burden the RMD places on each of them.

The 10 personal stories we have the honour to present in this year's Stene Prize Booklet stand for the more than 100 million people living with RMDs in Europe. Let's not wait until 2043 but continue our joint efforts today for improving their lives and to make our vision 2043 become the new tomorrow.

Prof Maurizio Cutolo
EULAR President
Chairman of the Executive
Committee of the International
League of Associations for
Rheumatology (ILAR)



"A great promoter of co-operation between doctors, patients and community workers"

The Stene Prize

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

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

Professor J J de Blécourt from The Netherlands, the first elected EULAR Vice President representing PARE, said about the occasion: "We may speak of an historic moment in the history of EULAR. The basic philosophy behind this development is the fight against rheumatism can only be effective, efficient and extended when not only the doctors (rheumatologists) but also the 'rest of the community' take part in the work of EULAR (the management of the fight

against rheumatism). This is a modern way of organising health care, research, fundraising, patient care, education, public relations, etc."

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

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

Rules of the 2014 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 2014, entry was open to people with an RMD aged 16 years and over. Entries can be submitted in the native language of the author and EULAR arranges to translate the 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 Prize is awarded at the annual European Congress of Rheumatology. The value of the prize is EURO 2,000 and EULAR also covers the cost of the winner attending the congress to receive their prize.

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



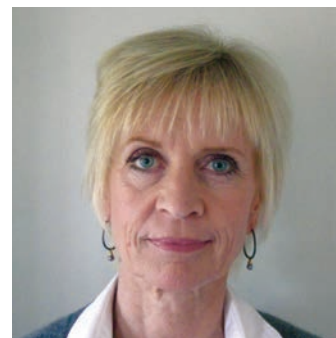
Diana Skingle



Marios Kouloumas



Jolanta Grygielska



Lena Andersen

The Edgar Stene Prize Jury 2014 – Meet the Judges!

Each year, a panel of people with experience or knowledge about rheumatic and musculoskeletal diseases (RMDs) have 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.

In addition to these five judges, the Chair of the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (PARE) and the EULAR Vice President, representing PARE, help to oversee the judging and offer guidance to the overall process.

Diana Skingle has recently started as the Chair of PARE so this has been her first time of being involved in the Stene Prize. Both Diana and Marios Kouloumas, the EULAR Vice President, representing PARE, serve as ex-officio members of the jury and are keen supporters of the competition. Marios was equally excited to be back again after he had supervised the competition as the responsible Chairperson in 2010 and 2011.

“What a wonderful opportunity!” says **Diana Skingle**. “The theme for this year’s Edgar Stene Prize competition ‘Vision 2043 – my ideal world for people with a rheumatic or musculoskeletal disease’ gave everyone with an RMD the chance to say how they would like to shape the future. People with RMDs face, and overcome, challenges everyday in their work life, home environment and in general society. They know what needs changing. They also know that their personal insights have the potential to influence other stakeholders and decision-makers into making change happen. I have always greatly looked forward to reading the essays of the annual Edgar Stene Prize competition booklet. Please join me. Read and be inspired.”

“Looking back 30 years, I would say that there have been

significant changes and very important steps in the area of rheumatology,” says **Marios Kouloumas**. “These changes, and, in many cases, revolutionary discoveries deal with the prevention, diagnosis, management and treatment, rehabilitation and research into RMDs. Looking to the future, 30 years ahead, I consider this year’s topic for the competition very important as it will give us the opportunity to hear the views of the people who are living with these health conditions. Through their views, we see first-hand what the challenges and obstacles that they face in everyday life are, as well as what their vision is and what their expectations are for the future.”

The jury members were delighted to invite people with RMDs to write about what they hope the world will bring them by 2043! Entries were sent to the EULAR secretariat by EULAR member organisations in Belgium Flanders, Belgium Wallonia, Cyprus, Czech Republic, Denmark, France, Germany, Hungary, Iceland, Poland, Portugal, the Former Yugoslavian Republic of Macedonia (FYROM), Serbia, Slovakia, Sweden, Switzerland and the United Kingdom. The response showed that many people are excited about what

technology has to offer people living with RMDs.

All the entries were of a high standard and each one of them presented a unique angle on the overarching topic so it was very difficult for the jury to choose the winner. In order to compare the essays, the jury members were asked to give ratings for creativity, writing skills and the inspirational aspect of the stories.

Jolanta Grygielska, PARE Board Member Poland, Leader of the 2014 Edgar Stene Prize jury

“It has been a pleasure and honor for me to be involved in the Stene Prize jury. Due to my many years working in organisations of and for people with rheumatic diseases, I was a member of Polish national jury on this project. Having the opportunity to work together with my fellow judges, and reading entries from different countries was an attractive challenge. It has been fantastic for me to read essays by people living with rheumatic diseases, sharing their emotions and experiences. This year’s theme ‘Vision 2043 – my ideal world for people with a rheumatic or musculoskeletal disease’ has given authors an opportunity to look at their lives and prioritise the barriers they



Gerd Jenny Aanerud



Pedro Machado



Jana Korandova

meet every day, and to name those which hinder them most to live life to the full. A 30-year perspective is long, but awareness of current obstacles is a first step in building a future world which is friendlier for people living with rheumatic diseases."

Lena Andersen, winner of the Stene Prize in 2007, Denmark

"Being part of the Stene Prize jury gave me the opportunity to learn more about how other people handle their daily lives with an RMD. The competition's topic is very interesting. I was diagnosed with rheumatoid arthritis (RA) 20 years ago and there is now a great difference in how people with an RMD are treated both medically and in society, at least in Denmark. I was very excited to read all the essays and to gain a lot of good ideas for an even better world – with new and more options for people with an RMD. To me, the Edgar Stene Prize competition is of great importance because this is where people have the opportunity to tell their stories, share their experiences and to be heard. My wish is that as many doctors and other health care professionals as possible will take time to read all the essays."

Gerd Jenny Aanerud, Norwegian League Against Rheumatism, Norway

"It has been an honour to be a member of the jury and I was inspired by the vision applicants have for the future. I am 54-years-old and RA has been in my life for 31 of these. I still work a small amount and do voluntary work to keep me active and busy. With new drugs I hope the future will be easier for everyone. Personally, I became involved as a patient partner in 1995 and as a patient research partner from 2002. For the last six years I headed a patient advisory board at the rheumatology department at Diakonhjemmet hospital, Oslo. Our task was to develop recommendations for how to include patient research partners in our country. I concluded this post and went back to teaching last year. Currently I work with ladies who want to learn Norwegian for various reasons. These are ladies who all believe in a future here in Norway, and working with them to realise this is most rewarding. I sincerely hope all patients will benefit from research and be able to work and function at a good level."

Pedro Machado, Rheumatologist, Chair of the EMerging EULAR NETWORK (EMEUNET)

"As a rheumatologist I have learned that there is no better way to understand how to help patients than spending time listening to them. Listening to patients, their feelings and fears, is a major part of our job and is key to better care. The Edgar Stene Prize competition is a unique opportunity to listen to patients' views about changes they would like to see to improve their lives and to create a better world for people with rheumatic and musculoskeletal diseases in the future. It has been a great pleasure and an honour to serve as an Edgar Stene Prize jury member and to learn more from patients' expectations and experiences."

Jana Korandova, representing the EULAR Health Professionals in Rheumatology, Czech Republic

"Thinking about the future, it is said that in 2050 our society will have changed markedly. Our life will prolong. Prolonged age will bring us more serious diagnosis. There will be more older people, therefore, more RMDs but fewer people will be able to provide the important

care and support to the ill people. On the other hand, a great chance exists in that doctors will know more about RMDs and the causes. Probably new, effective drugs will be at our disposal, also new and more efficient diagnostic methods. If we know the cause of the disease, we should know also how to handle prevention... That would be marvellous and I thought the vision of many authors would be focused this way. Well, this is how I feel about the topic. I really enjoyed reading all the essays to find out how people with RMDs caught hold of the theme."



Marinka



Family is everything



I love painting

Marinka Stein Due Sørensen – 2014 Stene Prize winner from Denmark

Originally from Ribe – an old and exiting city with a lot of history – 36-year-old Marinka now lives in the countryside near Silkeborg in one of the most beautiful parts of Denmark. She loves to visit the forest or to walk by the sea.

She has been married to her husband Michael for 12 years and they have two lovely sons: Valdemar who is eight years old and Storm who is three. She spends most of her time with her family.

Marinka is currently unemployed because of her rheumatoid arthritis, but she used to work as a teacher and is educated to teach literature, history, biology and arts.

She paints pictures and loves art in all forms. She reads a lot and enjoys being told a good story, whether it is a book or a film.

Keeping fit is important to Marinka so she works out three times a week and finds it also has a good effect on her illness.

In the summertime, Marinka's family visits different museums and marketplaces where they reenact the life of the Vikings. It is a hobby they can share as a family and they have a lot of friends in the "Viking society" from all over Europe.

How did you react when you heard you had won the 2014 competition?

Marinka: I was very proud and I cried a little because I wrote the essay right from my heart. When I hung up the phone I hugged my husband and invited him to join me in Paris.

You describe your life as a battle with the disease – what gives you the energy and a positive attitude in difficult periods of your life?

Marinka: It's simple: I love life and I love my family. When times are tough I look at my boys and I know it's all worth fighting for. My positive thinking is the engine that makes it all work. If I sat down and gave up it would be very sad and not a life worth living. Sometimes I am sad and the disease sometimes takes my breath. But when you have children you

have to rise and shine, and that is what I choose to do.

If you look back 10 or 15 years, what are the changes you can recognise?

Marinka: Medicines are more effective and awareness about the disease is better – knowledge opens doors! I have not used local support groups but they are very important for many people. The progress in medicine means a lot to me and I hope that the one I'm trying out right now will work and give me "my life back" – such as the ability to work etc.

What role could patient organisations, like Gigtforeningen, play in the future?

Marinka: A great big deal! They are already helping in healthcare debates. They also have great websites with information about medicines, the disease, how to cope when diagnosed etc. I hope they carry on doing just what they are already doing. They have helped me a lot!

What did you enjoy most when thinking about how things could be different in the future?

Marinka: I enjoyed thinking about what life without fatigue and without pain would look

like. And I enjoyed thinking that people in the future would have more effective treatment.

Among all your visions for 2043, if you could wish for one of them become reality now what would it be?

Marinka: A test that could determine which medicine would suit a person perfectly. It would make life easier if one doesn't have to try every medicine for three months or more to find out if it works or not.



My husband Michael with our youngest son Storm



Painting gives me so much pleasure

Dancing down the road of life

I imagine the road of my childhood lying before me, feeling the pavement beneath my bare feet, letting myself follow it, losing myself in the feelings and thoughts of bygone days.

I take the first tentative steps and let my thoughts carry me off to a time when the wind blew in my hair. How my tiny little feet ran and ran, intoxicated with the speed, an intoxication that spread to my stomach, forcing from me squeal upon squeal of childish delight.

"The feeling of freedom grows in me"

I remember carefree summer evenings with dew between my toes, splashing about in water and exploring treetops, looking for the next foothold. Those little feet carried me high and low. The world was mine.

The feeling of freedom grows in me, and fearlessly I take the next step along the road of my childhood; this step brings memories of a youth filled with pain, recollections of a slow, testing journey. Remembering how the freedom of childhood turned into a bodily imprisonment, dwelling on the pain, letting it enter me, allowing myself to be overwhelmed by it, wallowing in it.

The next step is a huge battle. It is

a battle against my own desire simply to give up – to give up and crawl into a safe hiding place away from the little needles that now cover the pavement. Yet the battle has to be fought – not just the battle against the disease, but also the battle for the right to exist in a competitive world where illness is unwelcome. Those stubborn feet, that stubborn spirit, take me several steps further. Memories of trying out medicines that don't work or have terrible side effects disturb me and beg me to carry on fighting. The little needles are still spread before my feet, beckoning, taunting; and feelings of powerlessness ride roughshod over my fighting spirit.

"It is a battle against my own desire simply to give up"

One mighty step more and I look back down the road of my childhood, my youth and my adulthood. I see my life as I have lived it up until now. I turn and open the door to the life to which the battle has led me – not just my battle, but the researchers' battle, the doctors' battle... The battle for the bearable, dignified, wonderful life offered in 2043.

My feet stride stubbornly, greedily, further on into life, and many

doors open along the way. The battle has ceased because my body is now able to work, to live. The researchers have found a way to tell which medicine will work for which person, so life does not revolve around spending time and resources trying out different medicines. Types of medicine have been found that work gently, but are so effective that the disease is suppressed, to the point that my feet now skip along without any fear of needles on the pavement.

My body is at peace, and the devastating exhaustion gradually leaves me as my feet dance along. The taunting needles have been swept aside and if ever they do creep back onto parts of the pavement, it is only for a little while because pain relief has become so much more holistic and effective.

In this life, we are not given a diagnosis to be hung up as a warning sign; we get a diagnosis but at the same time we are told that we can be perfectly healthy, happy and active people who have rheumatism. In this life, a person with rheumatism is regarded as a strong person – a person who is capable and willing.

Knowledge and shared humanity give us the desire to find our place in life, to discover what we can do better than anyone else. If our bodies sometimes endure a day's sickness, there is an effective

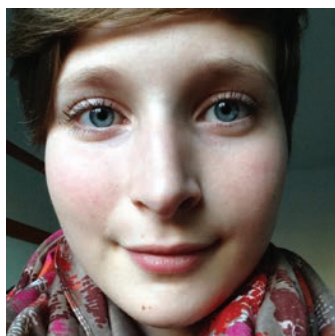
safety net that catches us, supports us and helps us. No more dreams will be shattered on that needle-strewn pavement!

"The devastating exhaustion gradually leaves me"

I stand in this life and let it embrace me, relishing the knowledge of how the battle has been won with the help of research, skill, understanding, humanity and those ever-stubborn feet.

While I bask in this embrace, I see my two lovely sons striding along the pavement, their father between them holding their hands. They are smiling and laughing, and behind their smiles there is no worry that something might happen that will hurt their mother. They are just genuine, joyful smiles. They let go of their father's hands, and their little feet carry them, wind-blown and squealing into my arms where they are met by a dance and a song of life.

This is my journey, but also that of many other people. My hope and my dream is that, like everyone else who has a rheumatic disease, I will be able to stand in this life in 2043 and reap the rewards of all the battles that have been so well fought!



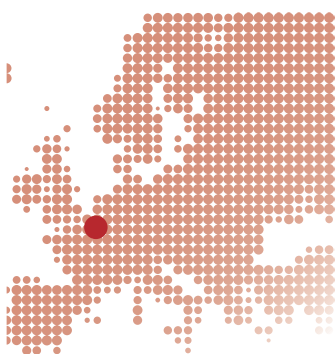
Aida Verstraeten



With my friends



Taking time out



Aïda Verstraeten Flanders, Belgium

My name is Aïda Verstraeten. I'm 18 years old and was raised by my parents in Stekene, a village in Flanders. I have a sister and, despite our differences in personality and immune system, we couldn't live without each other.

I study Dutch and English at Leuven University and, ever since I was little, I wanted to be a singer and a dancer. I will never be a dancer, for I have arthritis and my body is too damaged. But I have discovered I truly am a dancer after all – I dance with words. I hope to be a teacher one day... And a writer, of course, which a part of me already is.

Even if you have arthritis, this world is a wonderful place to be in. We know we can't change things that happened in the past, or improve scientific research instantly, but I like to think my writing might make a difference between looking at the dark or bright side of things.

Because we can

**Christmas Eve, 24th
December 2043**

**I am blinking my eyes
against the sunlight
seeping through the
curtains. I stretch out
and, although I have
been restricted in my
joint movements
since my teenage
years, I haven't felt so
supple for a long time.
And that's despite the
fact that I'm now 48.**

I turn around and press a kiss on the cheek of my husband. "Go and shave," I whisper into his beard stubble, "and then I'll make breakfast." He puts his arm forward to pull me against him, but I skilfully avoid him and, with a laugh, pull on my dressing gown.

For years, no more morning stiffness and, when I go along the hall of the top floor, images still flash before my eyes. My hand slides down the banister when I think back to all the times my husband would carry me up and down the stairs.

My days as a teacher wore me out and, as soon as I got home, my ankles and knees were no longer able to bear the weight of my too fragile body. But I was so

happy to do my job... And that it is still true now.

I can see the calendar hanging in the kitchen – 24th December 2043. I first met my husband about 28 years ago. Since then, he has done nothing but care for me and protect me from people who did not understand my condition – although I always said that it never bothered me.

**"The
inflammation
disappeared
almost
immediately"**

Exactly 22 years ago my son – my first child – was born. This was the first time that doctors talked to me about gene therapy. This was because RMDs definitely appeared to have a lot to do with heredity, and they knew they would eventually trace the defect in the immune system in people with RMDs. At first I just shrugged my shoulders about it despite being so afraid that my son would have arthritis, while knowing it was not something that would necessarily happen to him. I felt so damaged inside that nothing could drag it out of me.

But five years later, when I finally reached a really deep point physically, I decided to give gene therapy a chance. Not a bad decision, because the inflammation disappeared almost immediately. For a year, I had to take a heavy dose of medication that would suit my genes specifically. I was honestly very afraid – I didn't want it to change me. Would I get fat like when you take cortisone? Wasn't I even free to make decisions about my own body? What if it would change who I was?

At that time, it was something that not many people had made use of and it was very expensive. And on top of that, any form of medication could come with side effects. But in the end – and on the advice of my husband who could not stand that I was in pain again – I went for it.

Through a tiny 'mistake' in the stuff that I got through the infusion every month, I grew blond curls instead of straight hair. I had always wanted curls – until then. "This is not me any more," I whispered fiercely to my reflection in the mirror, but my husband turned me towards him and assured me that he still found me as sweet as before. What a joker he is – I still have to smile when I think back to it.



Enjoying some sunshine

"I still remember the happy tears rolling down my cheeks"

And now I'm here in the kitchen, and I'm making pancakes without a care. As soon as I realised that I could do that without fatigue in my muscles and joints, my husband decided, to my great joy, to teach me how. I still remember the tears rolling down my cheeks from sheer joy after I had been baking cakes and biscuits the whole afternoon without having to rest for as much as a minute. Or the time I walked through the park with my son who was racing after our dog...

I let our German shepherd out of his sleeping cage and give him the first pancake, which usually turns out wrong. Bambi does not care for it. Even his name, which sounds rather odd to human ears, doesn't bother him.

My daughter chose the name. She was born four years after our son, supposedly an accident, but I do not believe in accidents. The only unfortunate thing about her birth was the fact that she was more like her mother than I could really bear.

By now, they were able to discover before the birth whether the child had the disease or not, but in fact they could not. Uncertainty remained, but I pushed it into the background, but as soon as my daughter was six, I realised that something was wrong.

She complained increasingly about her knees. Before that she had not uttered as much as a whimper when she cut open her hands after a hefty fall from a climbing frame. But then there was gene therapy, though that did not work with everyone. My girl was not in pain for long, though the medication was not healthy for her little child's body. For her, it seemed to work, as it did for me.

"Hello, mum," I hear a voice say behind me, and I turn round. There she is, my beautiful daughter, now turned 18. She has exactly the same hair as when I was young. Her gene therapy was good enough to avoid those little mistakes and she makes a pirouette in my direction. "You looked so... worried," she says softly.

I turn away from the window and smile at her. She knows that I've had a lot of pain to endure in my life, but she does not know how that feels. She does not really remember it because she was little, though she remembers the

hospital and the infusions well – she used to try to pick it out of her hand.

She looks so much like me that it is sometimes painful. "It's alright, sweetheart," I assure her. I give her a kiss, drum my fingers briefly on one of the cabinet doors and have to laugh out loud when, reluctantly, she puts the plates on the table and begins to rattle things in the cutlery drawer.

"Meanwhile, thanks for the pancakes," she calls after me when I come out of the kitchen with Bambi and go upstairs again. I open the door of my son's room and urge Bambi to get him out of bed. You don't have to tell the dog twice to do that.

Then I walk back into the bedroom and look around in astonishment. Then my husband jumps suddenly from behind the door and throws me on the bed. I burst out laughing and still marvel at the fact that he does not need to be as gentle with me as he used to. No more unexpected pains.

"There are no pills involved"

"That was the wakeup call," he sniffs, seemingly upset with his arms folded. But then he comes to me, I lift my arms and he

carries me down the stairs. I don't protest, but as soon as he puts me down, I ask what that was all about. He kisses me tenderly on the cheek and says, "Because we can. Because I like you in my arms, arthritis or not."

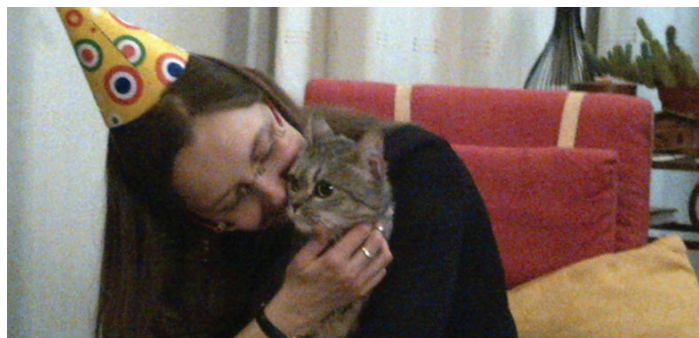
Before I can reply that I might well burst into tears because of the emotion, our son interrupts us. He stands at the top of the stairs, his brown hair tangled around his head and Bambi at his side. "Bambi's enthusiasm and my nose said 'pancakes'," he said.

"Happy birthday," I nod, and he laughs, and he stomps down the stairs and squeezes in between us. My thoroughly healthy son.

But if there's one thing more important than good health, then it's family. That's where I am blessed, and fortunate, because there are no pills involved.



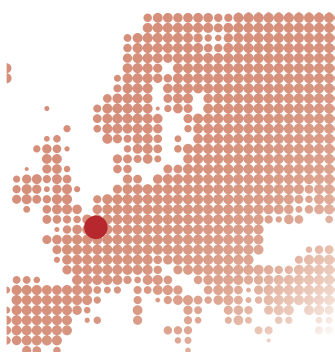
Marie-Laurence Jacquemin



Enjoying time with the cat



Out and about



**Marie-Laurence Jacquemin
Wallonia, Belgium**

My name is Marie-Laurence Jacquemin. I'm 37, live in Brussels and work as a EU project manager for an international non-profit association. I'm also a volunteer for the Belgian (French-speaking) patients association "Arthrites asbl".

I think I'm quite an active person. I study Arabic and I like to spend time with my friends. I also have a tendency to rescue lost animals. I can't always do everything I want because of my rheumatoid arthritis (RA) but I really don't think about it too much. I lead a pretty normal life.

I was very attracted to the topic because I am interested in the idea of imagining the future – I'm sure that it can only get better! I think being positive and looking towards the future plays a big role in learning to live with a chronic illness and not letting it get you down.

Living at top speed

It's 31st December 2043, and I'm getting ready for a New Year's Eve celebration. I love this time of year – it is great because it's holiday time. I go sledging with the children and have snowball fights. This year I did some snowboarding! I came a cropper a couple of times, but it wasn't serious and we all had a good laugh.

I have some resolutions for next year – to go trekking with some friends in India and to work a little less. I'll continue with sports, especially yoga!

Then I think about my aunt who had RA like me when she was young and wasn't able to do all that much because there was no suitable treatment. How lucky I was to have been diagnosed so soon thanks to

genetic screening! I even have made-to-measure treatment which works perfectly and has no side effects whatsoever.

"How lucky I was to have been diagnosed so soon"

In 2013, my aunt had to change her treatment several times because she could not stand the side effects, or because the medication had no effect on her. All that is ancient history today. Everyone has their own individual treatment and can live at top speed. No one has deformed limbs any more – that's all been consigned to prehistory.

On a professional level, there is a world of difference today. My aunt had to conceal her illness for fear of getting the sack. She had to give up her job as a journalist as it was too tiring, and had to take a secretarial post at a school. Even then, she ended up working part time in order to

have three-day weekends because two days were not enough recovery time for her.

When I see how I work myself, full time with business trips every month and lectures in the evening, I don't know how I would have managed if I had had to abandon my professional ambitions. Sometimes, you just don't realise how lucky you are!

"A world of difference"

To keep her job, my aunt had to make some major sacrifices, especially in her social life. She needed all her energy to be able to work. For her, it was out of the question to give up and find herself unemployed again. That would have been worse than anything – the precariousness of it, inactivity, feeling useless. It was much better to sacrifice her social life. I understand her, I wouldn't have been able to do any better. In the end, it depends on who you are, not everyone has the same priorities. It's a difficult choice.



Working at a conference



A great night out

As for me in 2043... I don't have to make this type of choice. I have a family, work that I like, as well as a very active social life. I do what I want. Here's to life!

"Not everyone has the same priorities"

More than that, I have no pain. My aunt tells me how much she suffered! She had to wait five years for her diagnosis – five years in which she suffered not only from the pain but also from the lack of understanding of the people around her. Not being able even to open a bottle, not being able to squeeze a tube of toothpaste, wash her hair or put on a pair of jeans ... Simple movements which had become impossible.

As for me, I never experienced anything like that. Genetic screening was so effective that I never had time to feel ill. How brave my aunt was! Having said that, she had no choice – she just had to get on with it.

Fortunately for my aunt, she still had the support of a patients' association. She says that they helped her a lot. Nowadays, these associations have all disappeared, because they no longer have any cause to exist. Everyone knows what RA is. It is a bit like diabetes or flu – everyone knows the symptoms. Patients are so well cared for that they don't even have the impression that they are ill. You are just like everyone else.

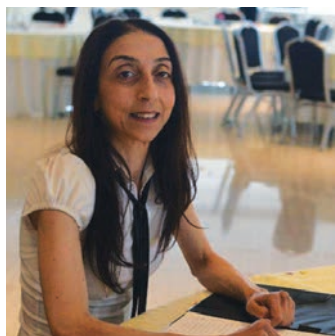
"Just like everyone else"

RA is not a problem as far as I am concerned. I don't even think about it. My treatment is a small tablet once a month. Down with it and that's the last you think of it! Sometimes I even forget it!

The other day, my rheumatologist told me that there would soon be a definitive cure for RA just as there is for other inflammatory rheumatic illnesses – perhaps starting as soon as next year. RA and the like, consigned to oblivion!

In short, I am forgetting about New Year's Eve – I must get ready! We are going to dance all night and it won't be RA that will stop me from doing that!

All the best for 2044!



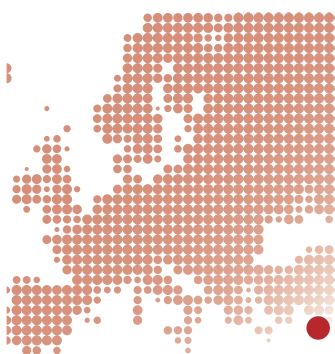
Chryso Kyriacou Yiasoumi



Me and my sister



Evening out with friends



Chryso Yiasoumi Cyprus

My name is Chryso. I was born in Famagusta in 1972 but now live in Larnaca. I have one sister and am married to Yiannis. My daughter, Irini, works in a tattoo studio.

I studied travel and tourism, and used to work as a waitress. Although I'd had lupus for almost 19 years, I was able to work. But seven years ago I had a lot of health problems and had to stop. At the beginning it was very difficult to stay home all day, alone doing nothing. Slowly I began to find myself and became an active member of the Cyprus League Against Rheumatism and Lupus Cyprus. I didn't let my illness control me. I have met wonderful people and made friends for life. I try to help people wherever I can.

I like to spend time with my family, and my hobbies are swimming and drawing. I have two dogs and a cat.

A world with no taboos

Because of the economic situation in my country, chronically sick people are having to face a great many problems. Living, as I do, with a rheumatic disease – and even though I receive a disability pension – I have lost the right to free medical care.

"There are not enough doctors"

From what we hear, things are set to get even worse in the near future. The hospitals are full and there are not enough doctors. There are waiting lists for all the necessary tests such as osteoporosis and MRI (magnetic resonance imaging) tests. Pensions and benefits

have fallen to very low levels and the chronically sick are facing difficulties even when it comes to the basics.

"Access to all buildings"

My vision for 2043 definitely has to do with better living conditions. I am hoping that this difficult economic situation will pass. I am hoping for better medical centres, and that citizens and politicians will be better informed about the issues of concern to rheumatic patients. The most important thing is for disabled people to have access to all buildings, be they public or private. There should be ramps and more disabled parking spaces. There should be rheumatology clinics in all cities in Cyprus which should be staffed by rheumatologists, paediatric rheumatologists and other specialists, nephrologists, orthopaedics, neurologists

and gynaecologists.

"Greet me with a smile"

As someone with rheumatism, I would like to be able to go to a place where I will receive the care I need straight away. I would like all my examinations and tests to be carried out quickly so that I can be given my treatment immediately and effectively. I would like to have all the time I need to explain my problems to my doctor. I would like a place where clerical staff and nurses will greet me with a smile.

"I would like to receive the care I need straight away"

I hope that by 2043 there will be proper physiotherapy areas where I can go to when I need to. I would like facilities to be



Yiannis, my husband



Family gathering



With my daughter Irini

the best possible and for physiotherapists to be knowledgeable about each individual form of rheumatic disease. I would like there to be a heated swimming pool I could go to every day so I can exercise more effectively.

As far as the future is concerned, I hope that the state will look after people with rheumatic and musculoskeletal disorders (RMDs) and that it will immediately respond to their needs. If such people are able to work, even for a few hours, they need to be in a suitable environment and have the support of their colleagues.

"Psychological support is essential"

Anyone unable to work should be given a disability pension which is enough for him or her to live on with dignity. Social workers and occupational

therapists should visit people with RMDs at home or at work should they need any help.

Psychological support is also essential – it should, therefore, be seen as necessary for patients to see a psychologist. I have systemic lupus erythematosus and there is no medication for my condition. For this reason, I hope that, by 2043, the pharmaceutical industries will discover medicines which will change my life.

"We too are people with equal rights and equal opportunities in life"

For me, the ideal world for people with RMDs is, above all, a world with no taboos. You shouldn't

be afraid; you shouldn't be embarrassed to say that you have a chronic condition.

"Discover medicines which will change my life"

We too are people with equal rights and equal opportunities in life.



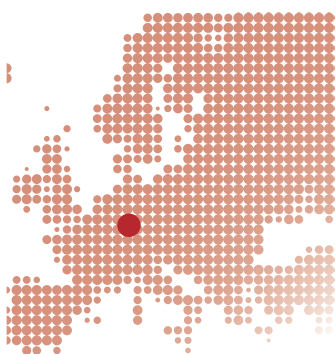
Yasmin Hrusch



Expecting



Fun at the zoo



Yasmin Hrusch Germany

My name is Yasmin Hrusch, I am 33 years old and live in Reutlingen with my husband Philip. We married in 2011 and my son Felix was born in March 2013.

I competed in the Edgar Stene Prize Competition in 2003 when the topic was about how difficult it was to find suitable work. Since then, I have found work as a teacher in a special needs school.

I have been ill with scleroderma and rheumatoid arthritis since 1993.

My essay is a conversation I imagine having 30 years from now with a grandchild that I might have.

Gaining control

“Granny, why have you got such funny hands?”

“Because I’ve got rheumatism.”

“Granny, what is rheumatism?”

“It’s an illness. You know, like when you have a sore throat and your throat is inflamed. My hands used to be inflamed and that’s why they look so funny now.”

“Granny, does it hurt?”

“When your Daddy was still a baby, it used to hurt me then. But it has got a lot better and there are lots of new medicines which really help. The Rheumatism app that I’ve got on my smartphone helps as well. Look, I just have to place

my thumb on the display and wait a bit and then the mobile tells me whether my blood is all OK or whether there is inflammation in my body. The app then tells me exactly what medicine to take and how much I must take. This means that I don’t have to keep going to give blood samples.”

“The Practice app shows me when the doctor is free”

“Granny, don’t you have to go to the doctor any more?”

“Oh I do, but not as often as before. The doctor gets all the results from my Rheumatism app via the internet. If I want to

ask him something, I can also send him a message via the Doc Messenger app.

“When will the rheumatism go away?”

Sometimes my Rheumatism app lights up red to tell me that I must make an appointment to see the doctor. Look, this is the Practice app which shows me exactly when the doctor is free for an appointment with me.”

“Granny, when will the rheumatism go away again?”

“I am afraid that it won’t go away from me, but even so I am well. There are even some things that I can be grateful to rheumatism for, because I’ve got to know some really great



Our wedding



Walking by the sea



The new family member

people because of the illness. You know, don't you, that many of my friends have rheumatism as well."

"Granny, when will I get rheumatism?"

"I really hope that you won't get rheumatism. But even if you do, it won't be so bad. Nowadays, doctors learn lots and lots about rheumatism in their medical studies. Not just doctors that specialise in rheumatism, but children's doctors as well, for example. And that's why rheumatism is found in children much quicker than it used to be, so the doctors can help much better as well."

"There are some things I can be grateful to rheumatism for"

"My physiotherapist has loaded some exercises on it for me which are good for my joints"

"Granny, what are you doing there?"

"I'm linking my mobile to the TV. Now I'm starting my Gymnastics app. My physiotherapist has loaded some exercises on it for me which are good for my joints. So that it doesn't get so boring for me, she has thought up a game for every exercise. For example, I'm supposed to move my shoulder joint and can now play tennis against the computer."

"Granny, I want to have rheumatism as well!"

"Nowadays, doctors learn lots about rheumatism"



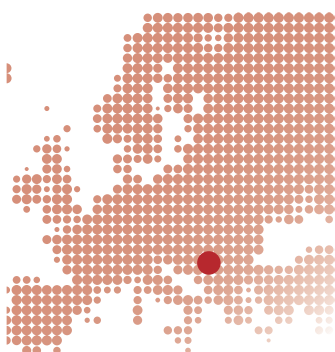
Pavlina Pejkovska



With my family



I enjoy being outside enjoying nature



Pavlina Pejkovska The Former Yugoslav Republic of Macedonia (FYROM)

My name is Pavlina Pejkovska, and I am a wife and a mother of two wonderful children. I was born in 1963 in Tetovo and now live in Skopje. I'm a professor of philosophy, logics and ethics by vocation, but I do not have a permanent job at the moment.

Since I was young I've been dedicated to literature as a reader and as a writer. During high school I worked as a journalist on the school magazine. For the last two years I have published texts on some local online media. In 2013, I published my novel "The Guardian" where I dedicated one chapter to rheumatoid arthritis and my struggle with it. Currently I participate in the race for best novel of the year in FYROM.

Through my membership of NORA (Non-governmental Organisation for Rheumatism and Arthritis) I gain information on how to manage this disease, and they help me immensely to not lose my courage for living.

Working together towards success

The future is a temple, our temple – one we should enter as dazzling stars, no matter whether we are healthy or ill. Therefore, our steps need to be cautious, our thoughts wise and our hearts full of love and hope. For the heart is always the last to age, unless it has been broken.

This human experience of the world should be reflected wisely in the mirror of the future as a vision of courage. That is why my experience in this world as someone who is ill does not put me off investigating, analysing, criticising and creating my own vision of a healthy future – not just for myself but for all beings all over the world.

I envisage the days when I am as ill as a chessboard. I am the one with the white pieces, competing to beat my opponent, rheumatoid arthritis,

with the black pieces. I approach every game with honesty and respect for my opponent, and I observe the strict rules of the game: caution when moving the black and white pieces; wisdom in making moves as the pawns, knights, bishops and castles make their way around the board; always keeping an eye on the queen; protecting the king; and a willingness to accept possible defeat.

"We are all part of a social, cultural and historical unit"

Anyway, in this game I place my hopes in the brilliant moves of humanity's collective consciousness. We are all part of a social, cultural and historical unit that collectively strives to attain the highest achievements in all areas. There is one goal: to make the life of every individual easier and more beautiful, so that we all can live a dignified life regardless of its duration.

I do not allow rheumatoid arthritis to undermine my dignity and bravely bear all the difficult moments in my everyday life.

"I do not allow rheumatoid arthritis to undermine my dignity"

Although there have been tearful moments, I have spent the seven years of my illness outsmarting my physical weakness through regular exercise, disciplined behaviour and keeping active – both at home and outdoors.

The present is the bearer of the future and the world aspires to be an ideal place for survival. The year 2043 is a distant point on the horizon for someone of my age, but this should not be a stumbling block to make me fall and drop out of the race for a healthy life in an ideal world.

That is why my vision for 2043 aspires towards the



Promoting my novel

engagement and functional correlation of patients together with their families, their communities, but most of all, with their rheumatologists. These last dear helpers of ours have been given the task of monitoring scientific developments in medicine, biochemistry, technology and ethics.

"I have spent the seven years of my illness outsmarting my physical weakness"

I give priority to achievements in medicine and to increasing living standards such as primary care for both the sick and the healthy. My vision's ideal is for medical practice to be the pinnacle of all positive energies in the universe. The energy will never be lost; it will always be there but in another form – as a cure for the body and soul.

"Never allow it to give up"

The body has to move and conquer spaces. We need to give it the free will to break down the walls of those bleak care homes and hospitals. Let it go outside into the open, to meadows, to sandy beaches and mountain plateaus. If necessary, let it cry with exhaustion from every joint, from every muscle, but never allow it to give up. We need to provide it with energy so that it does not falter.

"The pinnacle of all positive energies in the universe"

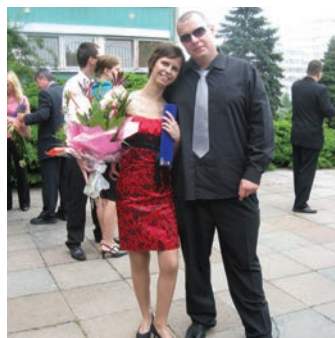
The spirit is stronger than the body. It is stronger because it knows how to bring in those closest to it with a kiss and a hug. It knows how to take to the stage without having to hide behind a clown's mask and lead

us to the secrets of the sincerest dance of the souls; one that will last a long, long time...

Success is getting your medication on time – otherwise rheumatoid arthritis will relentlessly push you into a checkmate. Any delay could be fatal.



Vladimíra



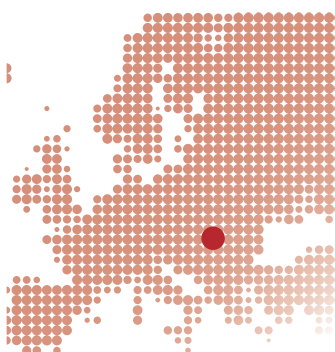
With my cousin at bachelor's graduation



With my beloved mum



With Barbora who sent in my essay



Vladimíra Barnincová Slovakia

I am a single, 26-year-old woman living with my mother in Bratislava, Slovakia. I became ill with juvenile idiopathic arthritis (JIA) when I was two.

There have been ups and downs in my illness, but with medication I have managed to hold down a job. I studied nursing and I work as a nurse in a hospital. I heard about the Edgar Stene Prize from the chairwoman of the Slovak League Against Rheumatism at a lecture one afternoon, and looked up more details on the website at mojareuma.sk.

I decided to enter the competition mainly because of the excellent topic, which has given me an outlet to share my dreams.

Vision, aspiration, dream or desire... This is how I will be celebrating

I am a 26-year-old woman undergoing treatment. I am being treated for many things, but it is “only” for rheumatoid arthritis – my constant companion for 24 years now – that I take drugs. I do not take medicine for my other “conditions”, either because no medicines have been made for them yet, or because they have yet to filter down to me.

Rheumatoid arthritis apart, my main “complication” is a constant muscle spasm on my face. To be specific, something tugs at the corner of my mouth, making me smile all the time – even when there is no obvious reason to do so. Complications never occur in isolation, so I have another, and that is my joy. Enormous joy from my “sick” life.

In the morning, I get up as soon as the alarm clock goes off, with a musical melody in my head which I cannot help sharing. Singing out of tune is not really

something that should be shared, but I have the audacity of a diva.

“Complications never occur in isolation”

As if that were not bad enough, I have problems with my sight. Whenever I look at anything, I see the most wonderful things. Take colours, for example. In grey I see white shine through, in the dark there is a roaring yellow, and in blackness I see a flickering green or sometimes orange. These colours form my world and I compare them to harmony, bursting energy, happiness and laughter. And as for ugly people? I know none!

This is not something I feel needs to be cured, but others say I am not normal, and they call me immature or a dreamer. But surely every winemaker enjoys young wine that has yet to mature, as it is exceptional in its freshness; and anyone who dreams has a rich life – and no one should deprive them of those dreams.

Now I have introduced myself, I can take you into my world. If you fancy, read on! There is even going to be a party, and you are all invited...

March 2043, Slovakia, preparations for my 56th

birthday...

... Please come in, no need to take your shoes off – the floor cleans itself when it gets dirty. You can hand your coats to my robot. We call her Polster, yes, that's right, like the polestar. Whenever you look at her she lights up, ready to do your bidding.

So, here you are in our home. It is my birthday tomorrow and my whole family is coming to celebrate. I have a large family. Ever since the language barrier disappeared, my children have dispersed all over the world. I live here with my husband. We have been together ever since I first clapped eyes on him and fell in love as a young girl.

I would like to prepare something for you to eat and to tell you about our life here. No need to worry about unripe vegetables or mutant meat – zero-nutritional diets are a thing of the past.

“I have had to make a few sacrifices, but it has been worth it”

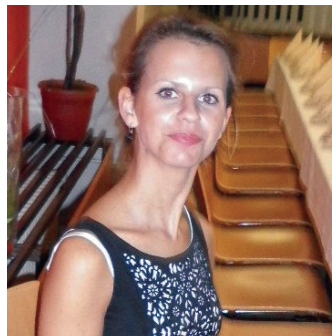
What will interest you most, I think, is my average day. I will try to find the words – so many have been coined that it is no easy matter to remember them all. Our



Slovakian delegation at patient organisations' meeting



Internship at the hospital



Going out



Dancing through the night

world has become easier with everything automated; my family and I have had to make a few sacrifices, but it has been worth it. Polster wakes us up in the morning, always choosing one of my favourite songs to do so. I sing along with her, although I have always been tone deaf.

She lays out the things we are going to wear, makes breakfast, takes care of the equipment and formats my "joint purifier", which absorbs the inflammatory molecules damaging my joints. It is attached to my navel, through which it draws out unwanted substances. It only operates when I am asleep because it is quite energy sapping. I don't have a lot of those molecules in my body, and many of my problems have been resolved over the years by diet.

Sometimes I don't even need to have the machine on the whole night, but my husband insists on it. He is a passionate paraglider and loves to take holidays in the countryside. These days, a patch of green costs a small fortune. Nothing makes him happier than when I am able to ascend a hill with him and take off from the summit. He has turned into that classic old husband, loving exercise and the wind in his hair.

The purifier has a little give in it so it does not get in the way of the activities of a married couple. Unfortunately, this purifier does not work with everybody who has rheumatism, and some have to have their joints replaced with self-propelling mechanisms. Recent advances allow their joints to be driven electromagnetically, but some older versions – even today – have to be plugged into the wall. I am still in employment as

retirement has been postponed "for the foreseeable future". In reality this means that you work until you drop. Dying is a rarity these days – if you do go, it is always very sudden. Otherwise, whatever the disease, life can be prolonged. But I will tell you about that another time... Please help yourself.

Over the years we have moved away from slaughtering pigs and cattle. We generally eat algae, spiders and insects. I would never have believed what a treat they are. Packed with calcium, iron and other essential minerals. My favourite are locusts, which are also high in protein. We are not fans of test-tube food in our family, but I will give you some to try. Because we treat the soil physically and chemically, I am able to grow tasty nutritious plants. But to get back to me and my rheumatism...

The last 30 years have brought major changes. I used to get to work and do my shopping by car, but these days it is virtually impossible to get anywhere by car, and you do not even need one. Everyone travels on the underground railway. People receiving treatment for movement-related disorders are granted a special permit allowing them to travel freely in airspace, so I make use of air transfers. Great progress has been made here, and my flying mini-bubble can get me around whatever the weather, which goes from one extreme to another, although meteorology does not affect me at all as I am safely beyond its reach.

There is no need to commute these days, and I work from home. I studied nursing and worked as a nurse in a hospital.

Now there are very few hospitals. Surgery is an outpatient procedure and those who are bedridden afterwards remain in their homes. Everything is monitored by cameras. When I am on duty, I go into my study. Here, I keep an eye on eight patients. I can see them, and they can see me. Everything is computer- or voice-controlled, and my instructions are performed by a robot – a nursing aide. Where I was once a bedside nurse, now I have become a self-convalescence programmer. I love my job.

"We have what it takes"

Other activities have also become much easier for us rheumatism sufferers, including everyday chores such as personal hygiene, housework, cooking and washing. I am afraid this wave of new information is starting to take its toll on you. Come and try out our bath, where you can have a rest. Do not be alarmed, it will undress you itself and immediately "wash" your clothes. We use synthetic cleaning fluid because there is not a lot of water left in the world. After cleaning your body, the bath drains automatically and fills with a new balsam fluid, which will get your blood flowing and will soften your body. A special cleaning process is used to remove perspiration and dust from clothes. Nothing is washed in water these days.

Your bed will be prepared for you after your bath. We sleep naked, and pillows and duvets are not necessary because the beds are heated and the temperature is regulated according to the temperature of your body core. The bed shape responds to your

body. For those of us who are "sick", auto-positioning is extremely comfortable. Even after all these years I am unable to forget those sleepless, painful nights, when I would have to remain still in order to doze off.

Well, good night, and do not forget to dream. It is very easy for dreams to come true today, as our thinking is 30 years more advanced in its intensity. See you at the party tomorrow...

... And here it is, I am another year older. I am pleased to welcome you too, dear readers, to my birthday party. Today I am 56 years old, and have spent more than half a century with rheumatoid arthritis. I am happy to see us all here together and, with this glass of exceptional and irreplaceable clear water, I would like to propose a toast.

"As we can see, the world outside is constantly changing and we must all adapt to it. Today, I am a contented grandmother, and I am still able to stand here before you on my own two feet. To work, to smile, and to see you in this most beautiful light. When I recall how, all those years ago, I was not meant to go to primary school because I was 'seriously ill', I feel a little tearful."

"But to get to the point... Whatever year it is, and however much we rely on all sorts of technology, everything boils down to what we are like inside, what our values are and the love we carry around inside us. My greatest birthday wish is to see crutches, canes, pain and wheelchairs disappear from the world... And for us to be free of burdensome doubts about whether we have what it takes. Because we do!"



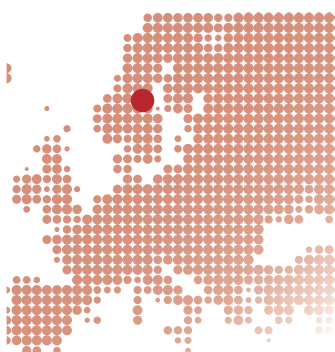
Maria Ahlriksson



Family on the podium



With my beloved daughter Ella



Maria Ahlriksson Sweden

My name is Maria Ahlriksson. I'm 37 years old and live with my husband, Samuel, and our beloved daughter, five-year-old Ella, in Jönköping, south of Sweden.

My interests are influenced by my illness. I was diagnosed with juvenile rheumatoid arthritis in 1988 but the disease "came back" in 2010 and I was diagnosed with adult Still's disease.

I have always been fascinated by listening to people's stories, their inner psychology and learning about God and theology. I am touched by how it relates to human vulnerability and the mystery of life.

Time with my family is very important and something I prioritise highly. When I have the time and energy I like to be out in nature – writing or painting a picture.

I work as a pastoral care teacher helping people cope when life hurts. My disease has actually helped me to live close to the fragility of life with all the pain, but also the immense gratitude and joy it brings.

The way ahead

The year is 2043.

In November I will be 57. My husband will be 61 and our daughter will be 26 years old.

Time has passed – and what a lot of progress has been made since I was given my diagnosis of rheumatism at the age of 11. Back in 1988 it was not certain that I would live to be a grown woman. Would I have a family? Would I be able to be part of that life?

As if by a miracle, I was given a clean bill of health, after which I was free of the disease for over 20 years. But at the age of 33 the rheumatism came back. The verdict was clear: "once a rheumatic, always a rheumatic..." But would you

believe it, now in 2043 a diagnosis of rheumatism does not mean you have a chronic disease. We are no longer constrained by our symptoms. There is no longer such a thing as "ill forever".

"We are no longer constrained by our symptoms"

Today, no one needs to struggle to force painful, gnarled fingers into gloves. No one needs to weep in secret and feel the salt tears on their cheeks because they can't even summon up the strength in their aching hands to make the pastry for a pie for the family's dinner.

No one needs to be hoisted down, body sprawling, into a special warm swimming pool while other people look away in fear and discomfort. No one needs to stand in the pool with the music playing and feel the worry, shame and frustration of not being able to manage the

lightweight dumbbells or grip the round ball.

No longer does anyone need to be a young rheumatic person surrounded by the stricken, pain-riddled bodies of older folk emanating combativeness after many years of imprisonment in their bodies.

No longer does anyone need to wake with a sore throat, thinking that it is just a touch of tonsillitis, only to be told, in the doctor's consulting room at the end of the corridor on the right, that they are so ill that they must be admitted to the county hospital.

Leave everything; now begins a journey you know nothing about...

A journey you have not chosen yourself, a journey that, over time, has brought you to loneliness, blame and frustration.

A journey that has raised a lot of questions but also, it has to be said, brought a strange kind of gratitude – somewhere along the way your senses have somehow become more fragile, and also much more open.



Enjoying being outdoors

Today, no one needs to live and be schooled for half the year in hospital, away from classmates and family, simply because their body is in pain and racked with waves of high fever.

Today, no one needs to have a face like a football, with a bull-neck and wispy hair because of the cortisone. No one needs to take medicine and worry constantly about side effects, knowing that if they could take only one thing with them to a desert island, it would have to be their medicine, of course.

No one needs to explain what rheumatic disease is, in all its different forms. Rheumatism has lost its stigma. That no longer exists.

No longer does anyone need to be compared with someone's old auntie or great-uncle who also had some kind of rheumatism – maybe not exactly the same as you, but still...

No longer does anyone need to be burdened with the guilt of having taken up so much of the energy, strength, time and worry

of their nearest and dearest...

There are no new findings indicating that you are to blame for being ill → that you chose the wrong lifestyle, the wrong eating habits or exercised the wrong way.

There is no questioning and wondering why you can't manage to look after the house and garden.

No longer does anyone make thoughtless comments about how many children a couple should have and how important it is to have siblings, or wonder why we have "only" one child.

"No one needs to struggle"

No one needs to worry endlessly that they **SHOULDN'T** have children. The medicines you take might also get into their little bodies.

No one needs to be anxious about the increases and decreases in their dosage, or the fact that when travelling on a hot summer's day they are carrying

potentially toxic injections around with them.

No one needs to struggle with not being able to open their jaw more than two centimetres. No one needs to lie there at the dentist with extra cushions and pads, with all the equipment scraping and buzzing away, always having to listen to the same words: look after your teeth, you are at high risk, rinse with extra fluoride, floss and brush, but still, it's good you have so much saliva in spite of all your medication.

No one needs to worry whether they are so ill that they will need to have extra vaccines in the wintertime... or whether they will become even sicker if they do.

No one needs to go to the hairdresser's and be told that they will never be able to grow their hair long again. It's not in good enough condition, and there's no point colouring it – the dye will not take because of the medication.

No one even needs to worry or fret about their children's future and whether this hideous

disease will be passed on to them. Feelings of guilt, like the disease itself, have lost their stigma. They have no power over you now.

"Feelings of guilt have lost their stigma"

It is with great joy and gratitude that I welcome these new times – times without tears, without pain and without loneliness. For the old has been made new.

The way ahead says you are seen, you are loved and I have confidence in you!



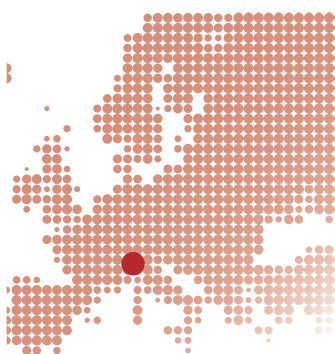
Emanuela Pavia



Hiking at Lac de Pignu



With my husband on our USA trip 2012



Emanuela Pavia Switzerland

My name is Emanuela Pavia. I am 40 years old and live in a little town called Niederhasli in Switzerland with my partner. I work in Zurich organising business trips. I love travelling and do this together with my partner.

I learned about the competition from the Swiss "forumR" where the Edgar Stene Prize was featured end of 2013.

I have trouble sleeping and am often awake during the night. Writing helps me to overcome fear and difficult situations. My therapist likes my writing and encouraged me to participate in the competition.

Getting back on your feet

"My life has turned on its head!"

"Then put it back on its feet!"

This is what I was told at my second consultation with the rheumatologist I had been referred to. I was completely flabbergasted! How was I supposed to make that happen? I could hardly move! I had no strength, just pain in my whole body! I walked slowly, so slowly in fact that I could see the grass grow.

The illness enveloped me in a gradual stealthy process and, for two years, has had me firmly in its grasp. The illness began quite harmlessly – itching in the face, a sore throat, salmon-red spots on the body, high temperature. Two days later, I felt severe joint and muscle pains throughout my body.

At first, antibiotics were prescribed. My blood counts deteriorated and so my GP decided to refer me to hospital. Quite fortunate, given the circumstances – Still's disease was the diagnosis of the duty emergency doctor. She told me it was quite a rare rheumatic illness. After a stay in hospital of just two weeks, I was discharged and returned to my everyday life – a life that I had to restructure. Simple everyday routine activities became quite a tussle!

How can a person cope with such an experience?

How does a person deal with this sort of diagnosis?

After my second visit to the rheumatologist and his statement that I should put my life back on its feet, I realised that the classical school of medicine was one of the potential routes towards recovery.

"I put on a mask and got on with everyday life"

In Ayurvedic teaching, rheumatism means "the lake of solidified tears". Healing would

only be possible if the illness were seen from its mental aspect as well. The diagnosis and this description became my ticket for the journey into my past.

My father died when I was 15 years old. I didn't have time to mourn – I had to play my part for my mother and for my small sister. A key feature of my childhood and adolescence was accepting that I had to take on the responsibility for roles and decision making for family members while I was still much too young.

Day in, day out, I put on a mask and got on with everyday life. My body sent various signals that this was all too much, but I ignored them or treated the pains with tablets. My life was something of a roller coaster until quite recently – work, family, relationships, friends, food and health. Until my body pulled the emergency brake, snatched the rudder to my life out of my hands and decided... not like that!

My vision for an ideal world for people living with rheumatism in the year 2043...

The new "health glasses" that have recently appeared on the market (in 2013 they are called



Beautiful Salzburg

“Google Glasses”) review my state of health when they are put on. Naturally, the doctor had configured them for Still’s disease and the related condition called rheumatoid arthritis with my personal data. My sleeping rhythm is transferred to the glasses during the night by a little transmitter and, early the next morning, the device recommends some yoga exercises to me.

“The device recommends some yoga exercises”

To accompany this, I drink my Ayurvedic health tea and, afterwards, I take the medication I have been prescribed. Internet research is no longer necessary because I can talk to my glasses. If I feel pain, I make an enquiry and straightaway I receive a recommendation to take a short break and a suggestion for a suitable lunch, made up of pain-inhibiting food.

Nowadays cars drive themselves, which is a relief for

people with rheumatoid arthritis. Mobility, whether it is for shopping, going for treatment or to the doctor’s, or for meeting people with the same frame of mind, is guaranteed. Even in the year 2043, mobility is of course indispensable. After the morning yoga exercises and a brisk walk at noon, my “health glasses” tell me my evening programme. All the data is recorded by the glasses and evaluated straightaway – for example diet, exercise, breaks, time spent at the computer, and how quickly a task was accomplished.

One recommendation was to watch a film of a romantic love affair on a home cinema screen because my feelings have got bottled up. That would enable me to laugh or cry unrestrainedly for a few minutes and give my feelings free rein.

Another time, a running programme was put together for me including power music from the iPod to encourage me to achieve my daily workload and strengthen my endurance. Sometimes my glasses even recommend having an hour of shiatsu therapy so that my energy channels are brought back into equilibrium. Psychotherapy is also supplied

by the glasses. The psychotherapist defines a set of key data which is stored in the glasses.

“Even in the year 2043, mobility is of course indispensable”

The doctor is always nearby if there is the threat of my readings plummeting. If the counts worsen, a consultation with the doctor is arranged at once. In 2013, doctors used to ask their patients how they were when they entered the consulting room. In 2043, the glasses are removed and connected to the computer giving the doctor all he or she needs to know about my state of health. Future procedures are gone over in a short discussion and I am sent home with an adjusted configuration.

Despite the “health glasses” having become an established part of the market over the past 20 years, the person with a rheumatic disease should be supported on all levels – physical, spiritual and mental. Holistic treatment should start

while the patient is still in hospital. Every person is an individual and carries his own bag of stuff around, filled with various unresolved problems, spiralling and unsatisfied behavioural patterns and stagnant areas of endeavour.

During the course of a detailed consultation, a doctor or psychotherapist could establish where the knots and blockages are in a person’s physical and mental makeup. The restricted consulting hours that doctors have in hospitals and in their practices make full and complete therapy impossible. This is why everyone should be offered conversational therapy and physical therapy in addition to the “health glasses”.

Complementary medicine should not be disregarded in the year 2043 either.



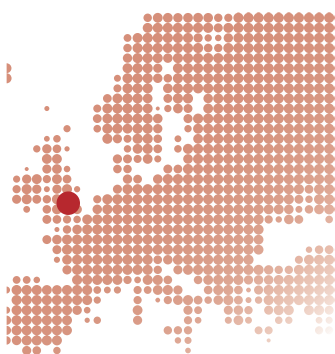
Liz Buckley



Great North Run in 2012



With my family



Liz Buckley United Kingdom

My name is Liz Buckley and I am a healthcare worker. I'm a 43-year-old single mum of two daughters (17 and 20 years old) and I live in Ruardean in Gloucestershire.

I have recently started to do some creative writing, so when I heard about the Edgar Stene Prize via the National Rheumatoid Arthritis Society (NRAS) so I decided I would give it a go!

I enjoy running and have taken part in the Great North Run as part of the NRAS team.

A positive outlook

It is 2043. I am 73. Rheumatoid arthritis is no longer the grim affliction I was diagnosed with in 1998. These days there is much greater understanding and far less mystery about the ways it differs from other forms of arthritis. Early diagnosis is now the norm – helping individuals progress well through those early weeks as they strive to accept who they are and who they may still become..

I still remember the dark days of diagnosis more than a year after my symptoms first began. I kept any grim whisperings of wheelchairs and permanently crooked fingers locked firmly away in some vague corner of my mind and made sure they stayed there. Being of a reasonably wilful personality, I characteristically went against the grain after diagnosis, refusing to take on board any suggestion of

slowing down—instead putting in for, and gaining, a promotion at work. I quickly decided a positive outlook was my only option.

“Acceptance always seems the hardest step”

Acceptance always seems the hardest step for anyone stumbling along the path of a recent diagnosis with this – or any other – potentially life-altering disease. A step not just difficult for the person being diagnosed but those who walk besides them are just as deeply affected.

“Professionals view their patient as the expert”

Even though my actual diagnosis took over a year, I am greatly indebted to the professor who eventually named my mysterious symptoms in 1998 and treated me aggressively straight away. In 2043, diagnosis is swift and responsive with continued support from family doctors and

professionals who view their patient as the expert.

In 2043, my two daughters are 47 and 49 respectively. I always hoped they remained healthy and free of the disease that has affected me throughout most of their lives. As they were growing up they learnt to live with my crickety old-lady-like fingers that worked perfectly well one day but not another. I quickly became the mum who was never going to win the parents sports day race at school. This fact never stopped me taking part though.

Through toddler eyes their child-like acceptance of things just being the way they were inspired me greatly. The most confusing and frustrating part of this disease, the inconsistency and haphazardness of the symptoms, becomes so much more difficult to comprehend when our more supposedly-sensible adult brains take over.

The heartaches and frustrations, misunderstandings and lack of compassion when it was a line manager or life partner who just could not – or would not – comprehend this haphazardness, remain a legacy of my most difficult times. They made me stronger.



Great North Run in 2013

In 2043 such problems are becoming a thing of the past. Rheumatoid arthritis is now much more widely understood as a systemic disease rather than a “type” of arthritis.

“No matter how hard things get, it is imperative to stay on top”

Although my girls may have missed out in some ways – and certainly had to grow up fast at a young age – I think my health problems helped them see that, whenever life strikes you down, there are so many more options than staying down for long. My only secret to managing this dreadful condition is that, in realising that no matter how hard things get, it is imperative to stay on top and never let it manage you.

It is really thanks to my children that I was able to remain in my health and social care management position for so long. Theirs were the tiny hands that did up buttons, placed hairclips and did up my shoes as I went off to work, taking my pain with me alongside little

magical words of strength, “You look lovely Mummy”.

My way forward has always been via acceptance and adaptation. How much easier this is in 2043. Suddenly, a way forward seems much more accessible for all. There is light at the end of a very long dark tunnel. Attaining this ideal world was simple – all it took was kindness and understanding.

In my life I remember several unsupportive experiences, especially in the workplace. But these days, in 2043, people with rheumatic or musculoskeletal diseases no longer feel as if they are the lepers of working society. The strength and forward vision of organisations like the National Rheumatoid Arthritis Society (NRAS) have led to a future full of support, alongside compassion and understanding in the more modern and forward-thinking workplaces of 2043.

Since those early days of diagnosis my own condition has improved greatly – although sulphasalazine remains my magic potion.

For a few years, once I started to get on top of the disease, I

began to run again. I owe a debt of gratitude to my GP, Dr Lane, who watched over my running; making sure I was sensible about my training and fitness monitoring. I ran to fundraise for the NRAS in the hope it might help find a cure. I ran just to prove to my girls I could. Although I finally had to give up in 2013 – my left knee insisted. Besides, I was 43 and it was beginning to feel like hard work!

There is an inexplicable and addictive pull to running – the rush of endorphins when conquering a new hill, the smug feeling returning home after an early morning run while most of the neighbourhood are still asleep. The runner’s high. Someone really should bottle it. Perhaps therein lies the cure we all crave? I think we know more in 2043.

After giving up running I could have become depressed, dwelling on the fact I was never going to fulfil my dream of completing a marathon. Instead, I stay positive, reflecting how far I have come. From being told at diagnosis a wheelchair was a very real possibility, to completing several 5k, 10k, a trail race and the

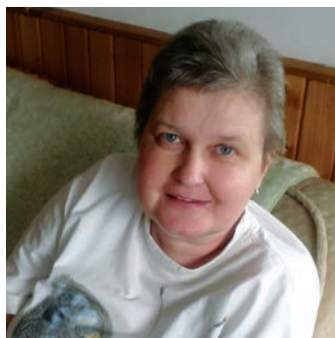
Great North Run, the world’s greatest half marathon. Twice.

That equals a marathon. It also equals two medals which now belong to my daughters – symbols of the power of self-belief, the ability to overcome whatever challenges life presents. My gift to them for the future.

Another gift is a joint gift from me and their auntie, my twin sister Jane. We are now part of the UK twin database exploring the genetic links of complex diseases such as rheumatoid arthritis. Maybe some of our contributions helped towards improvements in 2043?

I may have stopped running but one thing’s for certain— I’ll never ever stop dreaming. And I believe. Dreams can come true.

“The ability to overcome whatever challenges life presents”



Lenka Krejčíková, Czech Republic



Madeleine Lagorce-Coudert, France



Mária Hergovits, Hungary



Svava Theodórsdóttir, Iceland

Meet the other essayists

For the first time we are including excerpts from the essays written by those national winners who submitted entries but were not chosen to feature in full in the booklet

Czech Republic

Lenka Krejčíková

Železná Ruda, Czech Republic

Perhaps

All modes of transport have been adapted to accommodate disabled people – press the purple button by the door and a ramp slides out from the steps, allowing me to enter the vehicle with ease. People don't bat an eyelid these days. They have no issue with people in wheelchairs. They know that anyone with a large orange R on their wheelchair has serious problems and severe pain. It is all the better that we are accepted as equals by the people around us.

I make my way up to my specially adapted office and insert my timesheet into the punch clock. This is only for disabled persons as they have no precise time they have to be at work. There is no pressure – they arrive whenever they arrive.

I dictate my replies and advice in response to the day's mail into a microphone, and my adapted typewriter records my words on paper and faxes them to another office.

France

Madeleine Lagorce-Coudert

Tours, France

A place in UTOPIA

The sophisticated knowledge that we will have on the causative factors and their interactions will make it possible, in the main, to anticipate the emergence of the illness. We will have discovered the environmental factors responsible for the activation of this gene – whether they are psychological, physiological, dietary, physical or something else. In this way, the endeavours of researchers, those "artists working in the shadows", always aiming to increase understanding of the complexities of our lives, will be rewarded.

Hungary

Mária Hergovits

Kőszeg, Hungary

What I want

I want a more liveable and tolerant world.

There is a great need for effective assistance from society, including:

- expansion of accessibility and improvement of existing access, giving greater consideration to the safe transport of disabled people
- provision of frequent and free rehabilitation schemes
- treatment should be an automatic universal entitlement
- a physiotherapist should help each patient with the performance of targeted exercises in the course of rehabilitation treatment
- it would be important to ensure that people living with rheumatic disorders can return to work, eliminating their sense of redundancy
- free training should be provided on correct nutrition and a healthy lifestyle.

Iceland

Svava Theodórsdóttir

Selfoss, Iceland

A basic need

I hope that by 2043 people's tolerance will have reached a level where it will become generally accepted that not everyone is capable of doing the same thing.

That access to physiotherapy, massage, heating pads, psychological support and the equipment people need to make their lives easier will be considered a basic service.

It would also be ideal if the financial position of a rheumatism patient no longer had any bearing on whether they are able to receive care or, indeed, what kind of care they receive. This would no doubt mean that society would subsidise such care, because it constitutes a basic health service.



Brygida Widera, Poland



Maria José Castro, Portugal



Verica Djuric, Serbia



Yan Yishu, China

We have chosen extracts from their essays to provide an insight into what these authors see and hope for the future and to acknowledge their participation in the 2014 competition

Poland

Brygida Widera
Opole, Poland

Looking back 30 years

1998

It made me realise that it wasn't the disease that shut me off from social and professional life, it was society that was not taking my needs and rights into consideration. The world around me was designed for healthy people and I had been given the role of a sick person. Time for a change!

2043

For economic reasons, the principal emphasis will be placed on disease prevention. Today's medical and financial problems will be replaced by ethical ones. Questions will come to the fore: how far can we go in interfering with human nature, who should decide, what are the boundaries of controlled change, what will be the consequences of genetic improvement of humanity as a species?

Portugal

Maria José Rosado Balão de Castro Azeitão, Portugal

Benefit of flexibility

Apart from a doctor who is available, attentive, safe and competent, we need society to make our routine a bit easier. Flexibility in working hours (or alternatives to work if necessary), letting us engage in activities we need for our bodies – just like the oxygen needed for our cells. Furthermore, managing to organise our timetable frees us from the disproportionate, permanent stress that causes flare-ups: either we run from place to place to try to keep up or we decide not to run and anxiety kicks in because we know the mistake we are about to make.

Serbia

Verica Djuric
Belgrade, Serbia

Supportive society

Support groups are very well established. They enjoy the backing from society at large and have their own centres which offer high-quality rehabilitation. There is a network of these small rehabilitation centres where patients can go and benefit from many services: spa facilities, well-equipped exercise halls and creative workshops. The relationship between patients and care providers is a close one. In addition to professionals, patients also receive support from volunteers. Patients also provide help and socialise amongst themselves.

In everyday life, at home, on the streets, in parks and on public transport, a great deal has been done to install helpful devices, both large and small, which make life a lot easier for people with rheumatic and musculoskeletal problems. Every effort has been made to enable patients to cope with certain situations, regardless of their disability. Urban public transport vehicles now have special doors with grab rails suitable for people with RMDs.

China

The Edgar Stene Prize has been reaching out beyond Europe...

Yan Yishu Dalian, China

Not the only answer

The year 2043 will be a totally new era. Traditional Chinese medicine (TCM) will go hand in hand with anti-TNF therapy to treat rheumatic or musculoskeletal diseases (RMDs), and even find a way to cure it. The life of people with RMDs will be improved all over the world. What an exciting vision that is!

The combination of the TCM and anti-TNF therapy will make a breakthrough in the treatment of the RMDs. The anti-TNF therapy is a milestone in the therapy of rheumatic diseases and will develop further. However, the anti-TNF therapy alone is not the final answer. It is unable to solve the psychological problems caused by chronic pain.



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