



EDGAR STENE PRIZE 2015

TAKING CONTROL OF MY LIFE: WORKING TOGETHER WITH HEALTH PROFESSIONALS TO ACHIEVE MY PERSONAL GOALS

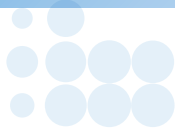


ENTER 

eular

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

**EDGAR STENE PRIZE 2015 TAKING CONTROL OF MY LIFE:
WORKING TOGETHER WITH HEALTH PROFESSIONALS TO ACHIEVE MY PERSONAL GOALS**



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

Contents

Editorial	4
About Edgar Stene and competition rules 2015	5
Meet the 2015 Jury	6
Winning essay 2015 from Denmark	8
Selection of essays 2015:	
Bulgaria	10
Cyprus	12
Czech Republic	14
Estonia	16
Germany	18
Hungary	20
Norway	22
Slovakia	24
Spain	26
United Kingdom	28
Meet the other essayists	30

STENE PRIZE BOOKLET 2015

EULAR Vice President, representing PARE Marios Kouloumas

PARE Standing Committee Chairperson Diana Skingle (until 13 June 2015), Dieter Wiek (from 14 June 2015)

EULAR Secretariat Maria Batziou, Birte Glüsing, Florian Klett

Editor Kate Betteridge

Co-ordinator Birte Glüsing

Graphic Designer and Print Production FC-D Ltd, London

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

Number of copies – 1,600

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



A time to reflect

I am honoured to have been asked to introduce the 2015 Edgar Stene Prize competition essays to you. I have long taken a special interest in the contest and it is my pleasure to present you with our winner Charlotte Secher Jensen from Denmark, and 10 runner-up essays from across Europe.

EULAR values the Stene Prize greatly. Written by people with rheumatic and musculoskeletal diseases (RMDs), each year the competition highlights the importance of the need for all three pillars of EULAR – the patients, the health professionals and the medical doctors – to work together.

As a health professional I have repeatedly heard stories similar to those featured in this booklet. They have helped me understand what living with RMDs means to different people and how it is possible to take control despite having a long-term condition. I am thus a great supporter of the Stene Prize – and think that the experiences shared in this format helps us move towards a more person-centred care.

This year is no exception and the theme is of particular relevance to me: “Taking control of my life: working together with health professionals to achieve

my personal goals”. Each national PARE member organisation first judged their country’s entries and chose one to put forward to the formal Stene Prize judging panel. A total of 24 essays entered the competition in 2015. I can only imagine what a difficult job the jury must have had choosing a winner!

As I read through the winning essays presented to you in this booklet, I noticed many shared experiences and themes emerging. Living with a long-term condition forces people to embrace life slightly differently, but successfully moving along a rocky road may, in itself, bring unexpected values into life. It is, furthermore, clear from the essays that people with RMDs want a partnership with their health professionals. They want to be listened to, respected and seen as whole persons. Through its 3-pillar approach, EULAR works hard to ensure the voice of patients is always included.

All these stories illustrate determination, perseverance and resourcefulness. They show how, if health professionals work with their patients, they can help them find their own way more quickly. The aim of treating people with RMDs should be to help them to be as independent as possible. But the patient needs to play an active and empowered role as a member of the multi disciplinary team.

Communication is such an important tool. For us as health professionals it is to listen, explore, encourage and share – to see the person presented before us, to work with them to help them achieve their goals. Some of these essays show the impact when this does not happen. I think all of us working with patients with RMDs might take time to think about our own roles and practices as we read through this booklet.

I would like to take this opportunity to thank all the contributors to this year’s Stene Prize booklet and I urge everyone to encourage friends, colleagues and peers to raise awareness of it. Let us remember that at some point we will all be patients. Let’s reflect on how we would want to be treated when that time comes.

Christina H. Opava

Prof Christina H Opava
Vice President, EULAR,
representing health professionals



“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 2015 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 2015, 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 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



Nele Caeyers



Kjerstin Fjeldstad

The Edgar Stene Prize Jury 2015 – 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 five 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.

Diana Skingle, UK. Chair, EULAR Standing Committee of PARE

“I look forward to the Edgar Stene Prize Competition every year so I was honoured to be invited to be an ex-officio member of the 2015 jury. The essays submitted by people with RMDs are always insightful, inspirational and enlightening. This year was no exception.

The theme ‘Taking control of my life: working together with health professionals to achieve my personal goals’ gave people living with RMDs the opportunity to tell us their experiences of overcoming some of the limitations of living with these diseases and of achieving things that they had thought impossible. Everyone has hopes and dreams. Living with an RMD often presents challenges to those ambitions.

However, by sharing personal aspirations with healthcare teams, and working together with them through shared decision-making, people with RMDs can set and achieve realistic milestones in order to reach particular goals. Whether those goals are to walk a longer distance each day, to be able to play with their children or to return to

work, they illustrate that people with RMDs can take control of their lives in meaningful ways that are important to each individual.”

Marios Kouloumas, Cyprus. EULAR Vice President, representing PARE

“It is a pleasure, once more, to be involved in this fantastic competition which has become very popular among people with RMDs across Europe. It is a very important tool for people with RMDs to share their thoughts, concerns and hopes for a better future, and a life with improved quality and dignity.

This year’s topic is very important, especially for people living with a chronic disease, because a successful life is one where the person can be actively engaged with their treatment and the management of their disease – as well as having the support of the health professionals.

I was interested to read this year’s essays to see how things can be improved – and how the people with RMDs are making their own decisions and choices for their lives and health in a partnership with the treating health professionals.”

Nele Caeyers, Belgium. PARE Board member, CEO of ReumaNet and Leader of the 2015 Edgar Stene Prize jury

“Reading and writing are two things that have been extremely important in my life ever since I was a child. Good stories and books offer me an unlimited way into imaginary worlds. Writing gives me the opportunity to clear my head and help others by sharing my experiences. Writing offers a way to get a grip on things that can be very complicated and demanding. This is why I fully support the Stene Prize competition and I have felt honoured to be part of the jury.

This year’s theme has brought back a lot of memories of the time I got my diagnosis of systemic lupus erythematosus (SLE). Unaware of what was happening to me, I put my faith in the hands of a strong team. But soon I was part of that team. We made decisions together and had lively discussions about treatment options. When I got pregnant, the whole group was equally excited! The role of health professionals can be so much more than only the medical part!

I have really enjoyed reading the inspiring stories from all over Europe!”



Costas Ioulianos



Dr Caroline Ospelt



Aïda Verstraeten

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

“It has been an honour to be a member of the jury for the Stene Prize. I have been inspired by the vision applicants have for the future.

This year’s theme ‘Taking control of my life: working together with health professionals to achieve my personal goals’ has given the authors an opportunity to look at their lives and how they have reached their personal goals. I have enjoyed reading their essays.

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 become involved in the Norwegian League Against Rheumatism 30 years ago. I have been a board member and a 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.”

Costas Ioulianos, Cyprus. President of cosmosrheuma+, representing the health professionals in rheumatology

“Firstly, I would like to say how proud I feel to have been a member of the Stene Prize jury panel. Due to my frequent involvement with people living with RMDs as a clinical physiotherapist, I have come to the conclusion that there is an imperative need to involve 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.”

Dr Caroline Ospelt, Switzerland. Liaison officer EMEUNET, representing the network of young rheumatologists

“Serving as a member of the Edgar Stene Prize jury has been a unique opportunity for me to get a more personal insight into patient’s sorrow and hopes. Even though I am a trained medical doctor, I have worked in basic research for more than 10 years. Work in the lab can sometimes be frustrating and tedious, in particular when you forget about the actual purpose of this work – namely to create knowledge that brings forward new therapies and a better life for patients.

Reading the contributions reminded me why the long working hours and the endless attempts before an experiment works are worthwhile. I enjoyed the essays and learning about the patient’s views on one of the most central topics in living with RMDs – taking control and working together with health professionals.”

Aïda Verstraeten, Belgium. 2014 essayist and representative of young people with RMDs

“I am 19 years old and from Flanders, the Dutch speaking part of Belgium. I am a language student, studying the Dutch and English language. I have a rare form of juvenile arthritis and have lived with two prosthetic implants (hip joints) for more than three years. Last year I was a participant of this competition and this year I have been part of the jury. Besides all of the sad and serious stuff, I don’t let my arthritis take over my life, even though it’s always there.

I am ambitious; I have dreams of my own, too. So this year, I wanted to know all about the personal goals of the contestants. I wanted to know where their passion comes from, what keeps them going and how health professionals help with that. Putting this into words for the Stene Prize might have been a huge step towards achieving whatever it is you want.

Just remember... Arthritis might be what you *have*, but it can never be what you *are*.”



My journey: trusting again



My journey: hoping



My journey: moving forwards

Living in the moment

Charlotte Secher Jensen
2015 Stene Prize
winner from Denmark

My name is Charlotte Secher Jensen. I am 41 years old, married and live in Gjern, a village close to Silkeborgin. I have two children: a daughter aged 16 years and a son aged 13.

I work part time for 12 hours a week as a sales supporter in a consultant firm. My tasks include booking meetings, and optimising transport and logistics.

Over the last few years I have read about the Edgar Stene Prize in the magazine *LedSager* from *Gigtforeningen*, Denmark's patient association, but the topic hadn't been quite right for me to participate. This year I saw the post on *Gigtforeningen's* Facebook page and the topic caught my interest.

I immediately felt that I had something to share. I chose to write because I wanted the health professionals at the hospital to learn how much a doctor or nurse's way of acting can change not only a patient's experience of the consultation, but also how the patient feels when he or she leaves the hospital.

I still remember that day... The day I was diagnosed with rheumatoid arthritis.

My thoughts were all over the place. They whizzed round and round in circles, in utter confusion. Why? What was it all about? And what now? That night – the night after that day – is what I remember the best. How I wept silently into my pillow until you could have wrung it out. How I crept into the kitchen in the dark so as not to wake the family, and turned the thermostat on the radiator up full. I remember the reassuring, monotone clicking of the radiator and the warmth, the meditative shushing noise it made, like the sea, calming, giving me a kind of artificial comfort.

"I sat there heavy hearted"

I sat myself down awkwardly on the hard kitchen floor and leant into the radiator's unfeeling arms, which gave me a warm, weak hug. I sat there in the dark, heavy hearted. I felt the burn on my back where, I hoped, I would one day have my angel's wings in my fantasy world. The burning pain gave me a few seconds' peace from the sharp stabbing I felt in all my limbs.

My tears dried up. Something happened. My thoughts folded their wings together; I took a deep breath and got determinedly to my feet. A battle was raging in my mind between light and dark. And the light won! I intended to live in the moment and in the future. This was my life. My decisions. But I quickly realised that I needed something to lean on. I had a long journey ahead of me.

I soon learnt the hard way that there are three different types of hospital visit. Those where I leave the place no wiser than before. A waste of time, waste of money and waste of the present moment. Then there are the visits where I leave in tears – either because I have not been seen or listened to, or because I have had to behave too much like a chronically ill patient.

Perhaps it was one of those visits where I had to have examinations that felt like a violation of my exhausted body and frayed mind. A doctor or a harassed nurse would barely look at me, giving non-committal comments, I feel as if I am just a number. They leave – I leave – with hopes dashed.

And then there is the last kind. My favourite visits. Those where the doctor or the nurse asks, "How are you?" and I answer, "I am very well." They nod, lean back attentively and say, "And how are you really?"

I am aware of the person beneath the white coat, the warmth of their eyes, that they want me to be well, to have a good life, in spite of the excruciating pain and powerlessness. They have read – or at least looked through – my notes. They remember my name. I am not a number.

"Take control of our illness"

Those visits are the light at the end of the tunnel... When you are way down in the dumps and the nurse smiles warmly at you and says that everything will be alright... That I can phone any time for a chat about anything at all. She has seen it all before – she recognises the powerlessness, the fear, the helplessness about medication and side effects. At long last there is someone who knows how to press the right buttons.

I feel the weight lift from my shoulders. It's going to be alright. My shoulders relax and I can breathe freely again. She gives me hope and belief that the present moment is OK, the future will be better, that it is possible to learn to live with rheumatism.

It takes time. Body and mind alike have to get used to the upheaval. And so do family and



My journey: making a start

2015 Stene Prize winner – Denmark

friends. You are no longer the same. Your body creaks and groans. I sit nervously in the waiting room and look around me. I am surrounded by people young and old. I am sure they all have rheumatism. Some have their loved ones with them; others sit there alone and wait. I feel the uncertainty we all have about the present and the future. No doubt we all have the same burning desire to make the best of our diagnosis, of our lives and to take control of our illness?

I sigh... Because of what is written in my notes, because I didn't get on with the lady doctor I saw last time, because I don't want her ever to write another word in my notes. I had strength enough and was able that day amidst all my hopelessness, disappointment and unbearable pain, to say no. The nurse and I had a good talk over the telephone as she had promised. She took the call in spite of her heavy workload.

"I meet his friendly eyes with a cautious smile"

I am nervous about who I am going to tell my life story to this time. Every time it feels like a

10-minute exam in which I have to relate as much as possible before my time is up. Not so much as a "Goodbye. See you again in three months. Don't forget the blood tests." I pretty well know in advance what it will be like. I feel anxiety weighing heavily on my pounding heart, and my invisible protecting wings cradling me so tightly I can barely breathe.

I catch my breath when my name is called. I look up anxiously and meet a pair of warm eyes. There he stands: the doctor, welcoming, leaning casually against the doorframe in a T-shirt, white coat unbuttoned, jeans and trainers. Still, I am on my guard. I sit down heavily on the chair and try to swallow, but my mouth is dry. I am almost unable to start my story all over again.

The doctor leans forward in his office chair. He leafs through my notes and I feel hope grow within me. I look at him, surreptitiously. I meet his friendly eyes with a cautious smile, which only widens when I hear the sentence: "So, how are you?" I hear myself lie. I answer him, "I'm OK."

He rolls his chair towards me and asks again, with a sparkle in his eyes. I feel relief and realise that I am smiling up into his eyes, even though the tears are

trickling slowly down my cheeks. Politely, he hands me a tissue, smiles encouragingly and examines me carefully but firmly, with a comfortable pressure. I relax. He scans my jaw, wipes away the clear gel from my cheek with a practised gesture, and comments, jokingly, that it isn't doing a lot for my hairstyle. I smile. No matter that it is still sticky all down my neck; he is forgiven. He hands me another tissue, so that I can try myself to remove the last traces without completely ruining my hairdo.

"We are both present in the moment. The tears stop"

While he is talking, explaining, reassuring, he holds my gaze. We are both present in the moment. The tears stop. I hear myself tell the truth. I even manage to recognise that it will not get better, that it is not going to go away but that it will still be alright. I am OK.

He listens, he sees me, he hears what I say. His words give me hope and his interest helps honest words find their way from my thoughts to my tongue. He carefully examines every joint of my fingers, and his warmth,

vitality and charisma flow out to feed my recognition that there is a life with rheumatoid arthritis. Maybe not the life I had dreamed of, but a good, full life.

"There is a life with rheumatoid arthritis"

I leave the hospital with a smile on my face. Outside, the sunshine dries the last tears from the corners of my eyes. I take a deep breath, straighten my back, feel my inner strength awaken and walk purposefully over to the car park, out into the world.

I am ready to live in the moment and meet the future. It is possible to travel with rheumatism in life's rucksack, provided you have help to pack it properly. I embrace the present moment and I embrace life!



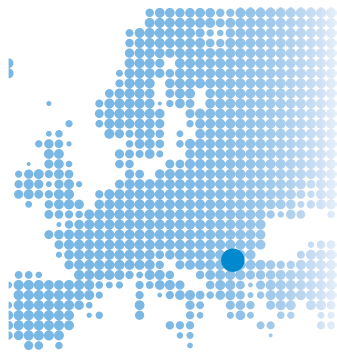
Penka Velkova



November 2014: going to the cinema



September 2014: trip to Banská



**Penka Velkova
Bulgaria**

My name is Penka Velkova. I am 39 years old and live in Plovdiv in Bulgaria. I am married with one child who is 11 years old.

I studied Bulgarian language studies in Plovdiv University and I have a bachelor degree. I used to work as a journalist on a small TV channel in Plovdiv. Now I am an owner of a small handmade crafts company.

I read about the Edgar Stene competition online on the Facebook page of Bulgaria's organisation for people with rheumatic diseases. I decided to share my experience and feelings with other people who face the same difficulties as me.

My spring

My life was like springtime – exuberant and bright. I had a happy childhood with dear parents, did well at school, married someone I loved and had a beautiful baby.

Then IT came along suddenly, uninvited – an insidious, unknown disease. My hands started to shake, my head rolled back and my heart was beating incessantly. I fell down into the arms of my love and all was dark. On the 5 May 2009 my spring turned into winter. I don't remember any of it. The days passed by with no memory of them. That was how IT found me, that disease I'd never heard of – lupus.

Day after day, month after month, for two years, lupus was my constant companion. I had lost my memory. I'd forgotten how to read and write. Once that happy and bubbly woman, I now lay in bed with blank eyes. I'd even forgotten that I had a daughter – the most precious thing in my life! This is what the disease did to me... Plus cerebral vasculitis, pericardial effusion, haemolytic anaemia, avascular necrosis of the hip joint, cortisone-induced cataracts and ascites. From 53kg, my weight shot up to 90.

My thick and wavy hair became thin and flat. My pulse – rapid; desires – none; my muscles – weak; insomnia.

But somewhere up there, someone had written about what should happen to me and when, and so a miracle happened! Luck found me.

“She showed me how to deal with the disease”

I first struck lucky with my brilliant doctors. I'm grateful and appreciative of everybody at the haematology department of Sveti Georgi General Hospital in Plovdiv. They're my guardian angels: the wonderful Dr Hristova, the caring Dr Georgiev and the irreplaceable Prof Goranov. Their accurate diagnosis brought me back to life. My eyes were reopened – sad and painful, but open!

But there was another guardian angel who came to me at the rheumatology department of Sveti Georgi – an incredible woman and a true professional with a big heart – Dr Stanislava Alimanska. I will be eternally grateful to her for making it possible for me to hug my daughter again and to be next to my husband. I thank her for every

moment I spend with my nearest and dearest. I'm thankful to her that my heart continues to beat as a mother, as a wife, as the child of my parents, as a friend. She will always have a place in my heart. She held me by my hand and showed me how to deal with the disease!

Dr Lina Stoyanova is also like a caring mother to me. Every day she would be by my side, and the words of kindness she whispered to me will stay with me forever.

And so, day-by-day, my spring started to return. The luck of having the right doctor and getting the right treatment brought me back, step by step, to life. The wonderful nurses and other hospital staff also played a part in my good luck. To this day, they still call me “our child”.

“I want the whole world to hear about it”

So do you see how lucky I am? And I want the whole world to hear about it! I've also come this far because of my wonderful husband. He was my shadow, never let go of my hand, didn't allow my tears to soak my clothes. He fed me and dressed me, and gave me air and light.



February 2009: with my husband Ventsi on my birthday, 3 months before the illness



May 2010: one year after treatment start – with my husband Ventsi and my daughter Roxena on her birthday



January 2012: trip to Barcelona with my husband Ventsi and my daughter Roxena



Oct 2014: with my family on friend's wedding party - me, my husband Ventsi and my daughter Roxena

And my dear mother – I cannot forget her despondent eyes and her hands when she stroked my hair that had been wrecked by the medication. While this horrible disease hung over me, my mother was by my bedside day and night! My eyes seared with pain, my trembling hands hidden, but her love and faith brought me back to life! My mother's tears flowed like a river and her kind words were my solace. She watched over me for months on end. Only she knows how much pain she endured. I'm also fortunate with my father, whose kind eyes were full of tears for his sick little girl.

That's my family. They are all my second piece of luck! I got to see my little daughter again after having spent two months in hospital. I was sad, despondent and frightened, but by now my thoughts and feelings had come back to me. And there she was, my daughter Roksena, my beautiful ray of sunshine. My little darling came into the room and said "mummy", which so warmed my soul. Without her noticing, I concealed my tears in her hair, and she just hugged and hugged me. Her little hands held a small necklace and she said: "This is for you, mummy! Wear it. It'll bring you luck!"

That's how I accepted the disease. I learned to say "good morning" to it every morning, and was happy to see the sun for yet

another day. I would go to bed and take the next pill wishing my disease "Goodnight". I got used to the changes in my appearance: I cut off my long, wavy hair; I accepted my body hair; and learned to love all of my 90 kilos. I would look people in the eyes as I walked down the street, with my black walking stick, because the disease was still gnawing at my bones and joints. But I kept on smiling, because for yet another day I could see my little girl's beautiful eyes, and could look forward to the following day when I could once again say: "Hello, life!"

"I learned to think positively"

My third piece of luck was my own life. It showed me who my real friends were. They were the ones who were next to me and by my bedside. They were the ones who didn't leave me sad and alone at home, but would take me for walks every day. Good, wonderful friends – there are only two or three of them but they have wounds from my pain. With their help, I kept on smiling and enjoyed every single small moment. I'll always have room in my heart for them!

My fourth piece of luck was myself. We have to learn to rely on ourselves and learn to have pure thoughts, words and

actions. What we think is what happens to us! I learned to think positively. The book *Mind Power into the 21st Century* revealed the essence of things to me, and that all my thoughts, all my feelings, all my words should be good.

The question I faced was: IT or me; the disease or life? There was only one option. I'm my father's strong girl, my mother's dear daughter, my husband's beloved and a mother to a beautiful daughter. I chose life!

To this day I remember Dr Alimanska's words: "We doctors are doing everything that's necessary. Your nearest and dearest are also by your side. However, if you don't help yourself, nothing will come out of it." So every day I started repeating positive words to myself. Every day I would say thank you for being able to see the sun and hear the birds sing, to love and be loved.

I learned some useful exercises for my body and eyes, yoga exercises and how to breathe properly. Along with my medical treatment, I also prepared herbal treatments. I discovered sticklewort tea – old people call it "young blood". I also had great trust in goji berries.

And so, 730 days later and the disease has gone away!

Remission... A word that I got to find out in 2009 and a condition

that I had been hoping for two years to see in my next hospital report. I achieved it thanks to all my pieces of luck. Things have carried on to this day in this way. I don't look back; I just look at the road ahead, and I think – and will continue to think – positively.

I never utter the word disease. or call my uninvited visitor by its name. I just call it "IT"; the thing that came and turned my whole world inside out. I'm sure IT simply bumped into my life to teach me a lesson. Have I learned and understood my lesson? I don't know. At least I'm trying my best, but I'm sure I have lots more to learn. I never asked "why me?" There are plenty of things that we can't explain, but we have to seek out their meanings and importance. For my part, I know that life is too short to waste it on insults, hate, and on bad thoughts and words.

"I love life and everything life has given me"

This is my victory and I have to carry on, because I love life and everything life has given me – a wonderful family, faithful friends and true feelings!

I hope that we all find our pieces of luck! And for me, my beautiful spring continues...



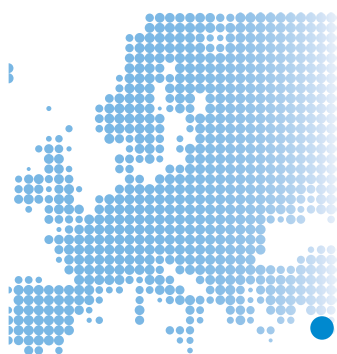
Souzi Makri



Holidays with Nicolas, my husband, in Greece



The cover of my book titled Yes I can



Souzi Makri Cyprus

My name is Souzi Makri and I come from Cyprus. I live in Limassol and I have two daughters – Simone who is 28 and a professional freelance translator, and Konstantina who is 19 and currently studying law in the UK.

I have been part of the volunteers' force of CYPLAR, the Cyprus League Against Rheumatism, for six years and I have participated in this essay competition before. I enjoy writing very much and my first book was published last May. It is a book about my experience with rheumatic disease – acceptance, feelings and actions.

I am very excited to have been selected to represent CYPLAR in the Edgar Stene competition.

Making a new start

Life is unpredictable, which means we always need to be ready to handle everything that comes our way. Sometimes things come to a dead end and we are forced to change course. So without complaining, without putting ourselves through the business of wondering “Why me?”, we set off along the new path life has pointed out to us.

Something can happen to any one of us at any time, something to make us reconsider our lifestyle, our way of thinking, our goals and the course we have taken in our lives. Whatever comes our way, there is always another side to it. And if we take the time to investigate that other side, it will teach us something, it will make us stronger. Every obstacle is also an opportunity for bigger and more creative things.

When I was diagnosed with chronic rheumatic disease six years ago, my life was turned upside down. I knew I wouldn't be able to do the things I used to do, the way I used to do them. I knew I would have to reconsider my behaviour and my way of thinking. Realising it is one thing of course, and accepting it and being able to make practical changes to your everyday life is a completely different story.

All this seemed difficult at first and made me withdraw and distance myself from my family and friends. I was angry, scared and insecure about the future... I was in denial and incapable of going on, as if my life had no purpose!

At some point along the way, after seeing a great many different doctors, I met one doctor with whom I felt comfortable discussing anything that was bothering me. He was empathetic and that made me feel safe. I started taking medication and, at some point when I started feeling a bit better, I decided to hold my head high and start living again. That was it; life began to have a meaning again!

I contacted an association for rheumatic diseases, where I felt I had found friends and even more than just that. The people there were very understanding, which was another stimulus to me in order to take back control of my life. After being told about the services provided by the association in co-operation with various health professionals, I registered for a “feelings self-management” workshop.

“I became aware of feelings I had been hiding”

I did feel slightly lost at first, but the psychotherapist helped me become part of the group. That was when I started to become aware of the feelings I had been hiding in my soul for a long time. Anger, insecurity, fear, lack of patience... Feelings I was neither able to handle nor realised I was experiencing. With the help of the psychotherapist, I experienced my feelings with pain and tears, going down what I would call a path of redemption. I discovered



With Spyroula David and Persefoni Markidou during our Train the Trainer course for RMD self-management



Our group on our self-management Train the Trainer course

practical ways to let my anger go, and ways to communicate with those around me.

I was, at the same time, also seeing a specialist psychologist, with whom I focused on behavioural and cognitive therapy. This helped me a lot, because I learnt how to change my way of thinking and how to stop seeing my condition as an obstacle to my life. Instead, I started seeing it as a spur to making a new start.

I was also taught how to change my lifestyle, avoiding certain things that exhausted me, taking short breaks from my work and going back to it after I'd had some rest. In other words, I discovered my body's limits, which I would have to respect if I was to be able to stay active and creative.

"I discovered my body's limits"

Around that time, I also started taking psychology courses at the Open University. Although I had to study a lot at a time when I

was experiencing memory problems and having difficulties, I didn't "drop out". It was hard work but it helped me a lot in dealing with the pain and the general problems chronic illnesses can cause.

On a psychology course which I was taking in my country, the psychologist presented us with a box of multi-coloured stones and asked us to choose one without looking at the writing at the bottom. I chose patience because it was obviously something that was missing from my life.

Alongside treatment groups and self-discovery workshops, I also started exercising every day. This was to help strengthen my muscles, which meant less pain. It was very difficult and a huge effort for me to get up every morning to go to the gym. A little aerobic exercise, stretching and muscle strengthening... It was hard at first and the great effort I had to put into it used to bring tears to my eyes.

My trainer, a rehabilitation specialist, was always there to encourage and support me. I would have given up without him! Slowly but steadily, I started improving. I was becoming more

flexible and my morning stiffness was reducing by the day. I find morning exercise very beneficial because it gives me energy and I am able to continue my daily tasks with enthusiasm and good spirits.

"This gave my life meaning"

With help from my psychotherapist and trainer, I began to feel better. I started working for the rheumatic disease association on a volunteer basis and this gave my life meaning, as I had stopped working while I was unwell. I also attended the chronic disease self-management workshop which taught me practical ways of coping from day to day, in the new circumstances of my life.

I learnt many new things through the seminars and workshops I attended and, for me, this is a new way of studying – a beautiful new path through knowledge, meeting people, humbly offering to my fellow human beings, being creative...

Yes, being creative. My experience with the disease gave

me the motivation to put things down on paper, to write a book, opening my soul to the reader, expressing all the feelings I have had all these years since the diagnosis, all my thoughts, my life's twists and turns, and the bitterness I felt every time the condition stopped me from doing something I wanted to do.

I am now training patients in self-management, transferring my knowledge and experience to them, which is great. I feel that with the guidance of health professionals, and with patience and perseverance, I have regained control of my life. My life is creative and I am feeling complete and happy.

"I am feeling complete and happy"

I have learnt that any unpleasant turn of events always has its positive side and, with the help of the right people, we are all perfectly capable of taking on responsibility for our lives.



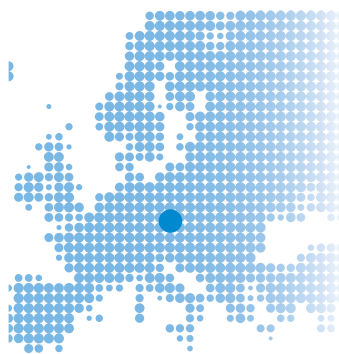
Ludmila Tomášková



I love horses



Leontýnka



**Ludmila Tomášková
Czech Republic**

My name is Ludmila Tomášková. I am 33 years old and live in Domazlice in the Czech Republic. I am married and currently on parental leave.

I heard about the competition from the head of my local Czech League Against Rheumatism club in Domazlice. I chose to participate because this year's Edgar Stene Prize theme interested me and I wanted share my own experiences with other people.

The power of words

Hello! My name is Leontýnka, I am three years old and I have already been through hell.

"I have already been through hell"

It started the day I was born. On that day, I first saw the beautiful light of the world. I was so looking forward to everything I had only known from sounds. To mummy, daddy, my brother, and all the wonders and mysteries of the world outside.

But then suddenly, alongside all that beauty, a hellish pain came that overshadowed all else. I screamed and cried. Wailing, I begged mummy for help. I cried all day and all night, and then immediately afterwards, again and again.

Suddenly I lost all sense of what day it was, of whether it was the sun or the moon that was shining. Everything merged into one enormous, relentless pain. All the beauty that I had been looking forward to so much had gone.

"I lost all sense of what day it was"

I could not see the outside world for the sea of tears in my eyes.

Mummy knew that she could not help me by herself, so she took me to see a doctor. And then another doctor. White

coat followed white coat as if whirling around on a clothesline in the wind.

"He tried to break my curse and deliver me from my torment"

Everyone turned mummy away. No one believed her. No one took her seriously. Oh, if only they could understand my wails. I tried so hard to tell them, but in vain. My efforts were rewarded with a high temperature. Daily pain alternated with nightly fevers of about 40 degrees. The one good sign was that I again began to distinguish between day and night.

The white coats whirled again in the wind, and no one stopped to listen. Until suddenly, one fateful day, my knight in shining armour came



Fun on the ice



This is fun and good for my hands

to my rescue, slashing through the pointless carousel of white coats and liberating me from my pain. He was the only person who noticed my wails, who listened to my mummy. He tried. For almost a year, he tried to break my curse and deliver me from my torment. But the riddle posed by the magician proved insoluble.

“The shackles of my torment slowly began to crack”

The whole time, I tried to understand. To work out what everyone around me was saying. As they did not understand me, it was up to me to make the effort. And then, all of a sudden, the turning point came... The day on which I helped my knight to rescue me. The day on which my lips moved and managed

to form the first fateful words. “My feet hurt,” I said.

“It will take time to struggle across the overgrown garden”

And it was then that the shackles of my torment slowly began to crack.

My knight now knew how to save me, and his lieutenants followed him. Mummy and I were no longer alone. They began to believe us and help us. The door of the bewitched castle started inching ajar.

I know that it will be a while before it is fully open. I know that the road beyond will be thorny and that it will take me a long time to struggle across the overgrown garden so that I can live completely free of pain.

But now I can speak, I believe that they will start listening. That the white coats will hear what I have to say and not just flap about uselessly in the wind. And, if not, I will speak, and keep on speaking, because my words have power. They have an immense power which has opened the door to my recovery.

“My words have power”

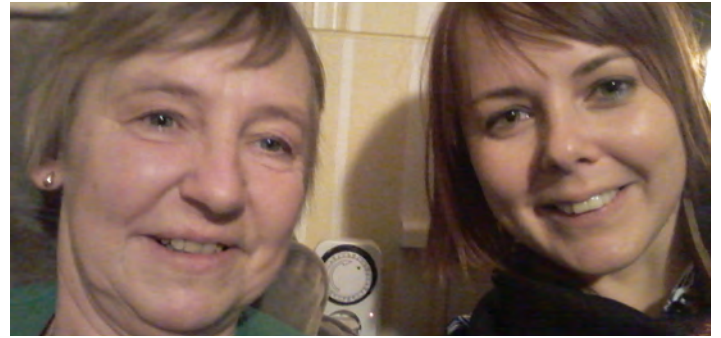
Believe me, I will go further and use my words to cure myself and, I hope, others.



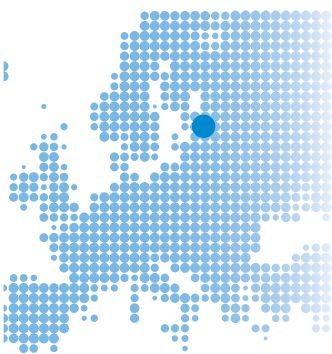
Triin Pobbol



Joy from walking in any weather



With my mother Liive



Triin Pobbol Estonia

My name is Triin Pobbol. I am 30 years old and work in a local county of Estonia as a director of the development and planning department. I am currently single and live in Paide which is my hometown.

I read about the contest from ReumaKiri which is published once a quarter and issued by the Estonian Rheumatism Association. After reading about the contest, I decided to share my thoughts and feelings about the disease.

Loves me, loves me not...

“He loves me, he loves me not. That’s what daisies were made for” sang a beloved Estonian singer a couple of decades ago. The daisy was one of my favourite flowers during my happy and sunny childhood. I loved running around in meadows and sometimes I would squat and pick daisies. There were times when I plucked the petals off the flowers to see whether I was loved or not. Many years have passed and it may be strange, but I miss squatting more than I miss picking daisies. Squatting is actually where the story of my illness started.

Loves me, loves me not...

“There’s nothing wrong with you”

It was summer 2012. It was just like any other Estonian summer – warm and sometimes rainy. I’d gone to discover southern Estonia with some family and friends, and one evening I went to tuck in my little cousin. I don’t know what made me squat as I was holding the child in my arms, but the pain that jolted through my left knee was unspeakable. Once I’d stopped crying, I decided to immediately show my aching knee to a doctor and that’s how I ended up in A&E for the first time. The very first visit among many... I was injected with a painkiller which allowed me to sleep peacefully, at least that night, and given a simple diagnosis – “there’s nothing wrong with you”.

Loves me, loves me not...

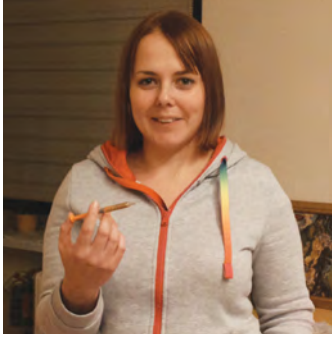
There are actually several doctors who have given me this simple diagnosis – “there’s nothing wrong with you”. Even before I ended up seeing a rheumatologist, I tried showing my knee to an orthopaedist and a surgeon. One day, I ran into a friend as I was leaving the clinic. “What’s the matter with you

then?” my friend asked. “Well, I was told again that there’s nothing wrong with me,” I answered as tears started rolling down my cheeks while I was standing there in the middle of the street. Because there’s one thing that’s worse than pain, and that’s not knowing what’s causing it.

Now I know that polyarthritis is a disease that doesn’t start by the book. Every person is different and that’s why the way the disease progressed was also different. Almost every book about rheumatism says that the disease first affects small joints and the joints ache in pairs but, in my case, it took a long time before 10-odd joints became affected by the disease instead of just one knee.

Loves me, loves me not...

It was a long road that finally took me to my present doctor and this doctor’s wonderful nurse. I have the best family doctor possible, who has written me mountains of different referrals and constantly keeps an eye on my progress. Even after I hadn’t been able to sleep properly for nights (my joints were stiff because of the arthritis and it was bothering me) and it was plain to see that I was limping, some doctors still



Needles are uncomfortable, but I am not afraid to inject myself



Family support is very important: with my brother and cousins on my grandmother's 100th birthday

wanted to convince me that there was obviously nothing wrong with me. The computer scan showed no injury and the blood test showed no inflammation. If the textbooks say that everything is fine, then everything IS fine.

"Everything IS fine"

Later on, fluid started accumulating in my aching knee so I had to have the fluid removed. The doctor who carried out the procedure looked like he'd watched the scariest horror movie the night before and was now eager to try something horrible on me. It really hurt so much that I almost passed out. Although I've had this procedure done to me several times since then, it's never hurt again. So it does depend on the doctor, after all.

"It does depend on the doctor"

Loves me, loves me not...

Things have to get really bad before they can get better, and this is why I finally ended up seeing my present doctor. This doctor's determination and desire to help me has given me back the joy of life that I was about to lose. The symptoms of polyarthritis – the extreme fatigue and the weight increase caused by medication – as well as not

knowing what the future may hold – were (and sometimes still are) unbearable to me.

And then there's the pain. The all-encompassing pain. I can say that my doctor started to understand me. Yes, they also did tests, looked at images and assessed my joints. But they listened. Once, there was a long queue behind the doctor's door. I thought it looked like a conveyor belt and I wouldn't have the time to tell the doctor about my concerns. But no, they listened to me and dealt with my concerns.

Thanks to them, I've been receiving biological treatment for six months and, earlier today, I signed my consent to take part in the tests of a biological drug for the next 266 weeks of my life. I trust this doctor with my life.

Loves me, loves me not...

The husband is the head and the woman the neck in the family and, likewise, every good doctor needs a dependable nurse who supports and helps the doctor. My doctor's nurse Kati seems to be just like that.

The first time I met Kati, she learned that I hated having my blood taken. I just passed out in her room. After that, she has tried to hit the thin veins in my arms dozens of times. But if the blood doesn't want to come out, it won't come out. One time I noticed that Kati was seriously worried that she would hurt me and I would get dizzy again and

maybe we should go to the blood centre, as the only thing the nurses working there do all day is stick needles into people and draw out blood. "But you've always done it, so you can do it today as well," I said to console her and, indeed, she managed to take my blood once again. I trust her with my life as well.

Loves me, loves me not...

"This doctor was determined to help me"

My journey to biological treatment and the hope that one day I may wake up and feel no pain at all has been a long one. I know that, although I'm only 30 years old, I've found myself a "lovely companion" in the shape of inflammatory polyarthritis and this companion will stay with me until the end of my days. Yes, the biological drug makes it easier, prednisolone and diclofenac and other drugs also make it easier, and I have the support of my doctors, but... One Sunday when I was laying in bed and going crazy with the pain and the exhaustion, I made a decision: I would become my own biggest critic, friend and lover.

I decided to move every day. The hardest and longest step for anyone trying to exercise is from the sofa to the front door, but doing it when it feels like

everything in you is in pain except for the nail on your left big toe and the seventh hair in your right eyebrow makes it particularly difficult.

One of my friends urged me to go for walks in the morning to kick-start my days. This morning exercise with the stiffness of joints is even more difficult – it's not just sleep trying to hold you back, the pain also gets in the way. My friend promised to come with me the first time, but she was still fast asleep at the agreed time. I have managed to kick-start my days with these walks on several mornings, but being mobile in the evenings is still more my thing.

Today, I will also go for a small round of Nordic walking in my hometown to celebrate the start of the biological drug tests that I will be a part of for the next 266 weeks. I don't care about the snow and storms and the dark Estonian winter – I feel that my good doctor, the drugs that work a little and my will to love myself give me some hope. I've decided to live my life as well as possible with the disease I've got.

Therefore, loves me, loves me not... I LOVE!



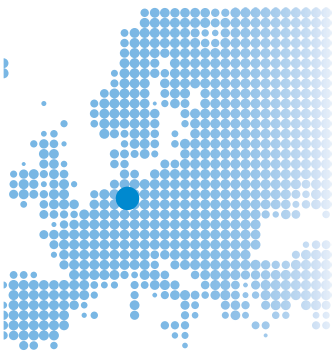
Maiken Brathe



Our Acki in 1985



Me in 1984



Maiken Brathe Germany

My name is Maiken Brathe and I come from Elmshorn, near Hamburg in northern Germany. I am 44 years old. 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 German Rheumatism League's periodical *Mobil*.

On aliens, records and pipe smoke

My first years with rheumatism resembled a science fiction film – it was 1980 and I was 10 years old. I was lost, not only in pain, but also in my life. My parents did not believe me when I could hardly walk in the morning and play in the afternoon. Even a stubborn attack of fever did not help me to be believed – instead it gave me the status of something special. I now counted as an “interesting case” in the countless clinics in which I was passed around from doctor to student, from auditorium to lecture hall.

And when I asked what was happening to me, what examinations were being carried out, whether I was going to die, I never got an answer. I felt as if I

had been spirited away by extra-terrestrials who dressed in white coats and masks, strapped me to tables, stuck needles into me both front and back and experimented on me. I couldn't understand them. They were not from my world.

Three years and two hospitals later I was sent to a rheumatology clinic for children. I was all skin and bone, and unable to walk more than three steps. People in white coats – aliens in my eyes – caused me to panic.

“We have all succeeded in getting our lives and illnesses under our own control”

When I first met my new ward doctor, Dr Ackermann, it occurred to me that he was just like an absent-minded professor from a children's book. His greying hair was generally unkempt, his white coat was creased and the glasses perched on his nose hid his

eyes from view. He smelled of pipe smoke, which is how people often knew where he was at any given moment. I liked that because that made it possible to get out of his way.

On his rounds, he would pick up the pictures that I had painted to look at them. I snatched them away from him. That was too intimate for me! He might well have needed to potter about in my veins, but not in my creativity! When I hid the pictures under the blanket, he would look at me in shock with his hand still out stretched. He was absolutely paralysed and I understood that my behaviour hurt him.

That was new. I was capable of hurting his feelings! The doctor! The alien! If I was able to wound him then he had to be on an equal footing with me! Instead of being an interesting case, a child without a say, I had become an actor!

The germ of trust in this man, that we children called “Acki”, began to sprout. I started talking about myself, about my pains, my fear of the needle and bad prospects. Dr Ackermann did not fob me off by saying “everything will be all right”. Instead he was ruthlessly honest. For me, as a 13-year-old



Today

girl, that was the highest form of respect that a doctor paid me. Being honest.

Acki had no time for tears. Instead of comfort and handkerchiefs, there were challenges like listening to my inner voice, recognising my own needs and trusting myself – because not every therapy suggested by a doctor was actually appropriate. In the past, other clinics have shown this and I bear the proofs of this in the deformities that I still have in my hands.

Knee punctures made me scream and howl. Acki did not scold me but remarked drily, “Your neighbour in the ward is waiting outside and she is younger than you. You’ll make her afraid.” I didn’t want that and so I pulled myself together. Caring about other people... That’s what he was teaching me by saying that. And after the puncture, he would say, “Many congratulations, you have broken the clinic record! So far, nobody has had so much fluid on the knee as you.” I was 13 years old and proud of my record.

Somehow, in the operating theatre in the basement, I began to notice what I gained from having rheumatism, quite apart from the points scoring and being a record holder. By this, I don’t mean free periods in the lesson timetable or more time to write class assignments but recognising the social skills that I

learnt through my illness. At the time, of course, that’s not what I called them, but I understood that I was certainly entitled to hold my head up straight and self-confidently, even if the rest of my body was twisted and painful.

Through Dr Ackermann’s instructions to listen to myself, I gained control over my situation. He did not gloss over where I was starting from, nor did he say I was crazy when I set goals for myself that I would never be able to achieve. He taught me to follow my goals but not to fix my gaze on the unattainable. That would only discourage me on my way. I was to concentrate on the little steps and stages, and aim for these.

Without anyone needing to point me in the right direction, another achievable way opened up for me. I never did become a reporter in Chile, but I did complete my studies in German and journalism. And that despite my teacher at the time taking bets on whether I would ever manage to do my A levels because of all the hours I missed through illness!

During my teenage years, Acki’s and my opinions often clashed and harmonised as well as mud packs and ice packs on the same joint at the same time. We often argued over political topics, though disputes were also a game between us – a mixture of teasing, serious exchanges of views and a type of mutual liking.



Dr Ackermann in 2012

Each dispute fuelled my maturation process towards independence.

Acki is dead now. He died last summer. We stayed in contact throughout the years. I had known him for over 30 years. Through social networks I asked former patients whether we should put into words what our ward doctor had meant to us for his funeral. Plenty of contributions trickled in, some of them from children from different decades whom I had never known!

I could see myself reflected in all their messages. These people expressed in words what “Our Acki” had embodied for me. “Life saver”, “Second dad”, “Confidant”, “inspirational”, “a bit crazy”, but a HUMAN BEING JUST LIKE US!

“Without respect and empathy, the best training qualifications amount to nothing”

Overcoming challenges, accepting the illness without being defeated by it – that is what we learnt from him. Without him, we would probably never have seen the fragrance of pipe smoke

as something good, and many of us might never be playing chess today. Without “Our Acki”, none of us would have become the people that we are today.

Dr Ackermann had no children of his own and yet, at the same time, he had more than you could believe possible. That’s us – his former patients from several decades! All of us with a firm footing in life, even if our stability is based on rheumatic feet or prosthetics. We have all succeeded in getting our lives and illnesses under our own control.

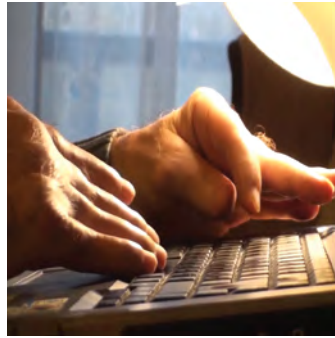
Doctors are not gods in white, not aliens – they are people from my planet and, if they want to, they also speak my language. I learnt that from Dr Ackermann.

Without respect and empathy, the best medical or therapeutic training qualifications amount to nothing. Acki already possessed these tools at a time, in the 1980s, when people in many places still thought that rheumatism was an old person’s disease and that sick children were just interesting cases. To me, a handicapped little girl, he restored my self-esteem and my dignity.

His eye-to-eye encounters with me helped me and hundreds of other sick children to discover and nurture new capabilities within ourselves – ruthless optimism, toughness and a belief in myself. And belief in a happy ending. Despite rheumatism. Or precisely because of it.



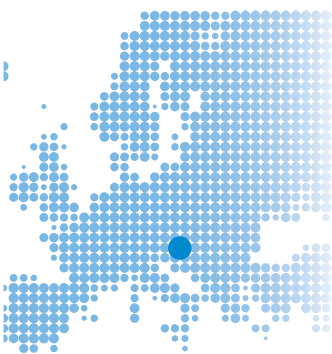
László Adamecz



Typewriting my poems



Nostalgic mine visit



László Adamecz Hungary

My name is László Adamecz. I am a retired miner living in a country town in Hungary called Tatabánya. I am 68 years old, married with four children and a grandchild.

My mission is to help other people with RMDs to overcome their problems and teach self-management by means of body and soul.

I learned about the Stene Prize from the Hungarian rheumatism league.

There's life and opportunity beyond the pain!

At the age of 33 I was a proud, strong, hard-working miner when, in the autumn of 1980, polyarthritis suddenly set in following an accident-related knee operation. My limbs stiffened; my health fell apart within a few months.

For the sake of my three young children and their future I did everything I could, even though I collapsed many times at work. For months my wife had been helping me to get dressed and this reality check gave me a huge shock. At the height of my strength I had become unable to do anything because of pain. I just had to accept reality: I was not able to do anything useful for my family or myself.

Even though I thought I was strong, sometimes I cried. I was very ashamed of this, as well as of the fact that I was walking in a strange way. In the summer of 1985 I had no option but to accept retirement. This was, for me, the biggest failure. I was

living in a numb, isolated way. I was looking for any possibility of change, but my weakness and pain stopped me. Today, I now know that there is life and opportunity beyond the pain!

“There is life and opportunity beyond the pain”

The length of my stride was the mere length of a foot, and I was steadier on my feet when somebody was holding my arm. I was only able to sit down or get up if I rested my elbows on the table. Due to the severe pain I did not even go for the treatments and as, a defence mechanism, I was moving less and less. I felt envious of all the people in wheelchairs, because “they do not need to walk”. I was desperate to retain my ability to drive.

I met a physiotherapist, Erzsike, who wanted to help me. I was uncertain and I felt ashamed that I had been so unlucky so young. Despite my weakness she accepted me (whilst I have only accepted myself years later). She

placed me carefully on a mat and we did careful exercises, which I then had to continue at home as my homework.

Later she asked, “Mr Adamecz, have you done your exercises?” I was quite startled but, in preparation for her asking this question again, I forced myself to do the exercises because I could not lie – especially not to a person who was helping me with so much commitment. We have remained friends to this day. She was my witness at my wedding and is godmother to my daughter, Anikó, who was born in 1996.

After I wake up, the daily exercises are now part of my life as a ritual. I slide down from the settee onto the carpet and, after the stretching exercises, I climb back onto the settee and continue with my sitting-down exercises. I smile at myself, at my clumsy movements – though who on earth could move any more gracefully with so much stiffness and pain? A slight improvement in my movement and physical condition has encouraged me to continue with this because I must not just let myself go.



Daily exercises are part of my life

The stiffness in my wrists and fingers caused great pain but, even worse, people used to call me “crippled” behind my back. I had a number of therapeutic treatments in hospitals and sanatoriums, and had quite a few surprises. A very kind nurse told me that if I got cramps in my fingers at home I should have them bandaged onto a chopping board covered with parsley. I almost laughed at her as I had never heard anything like this before.

“I must not just let myself go”

Two months later this was no longer so funny when the fingers of both my hands had to be straightened out. Underwater exercises, individual exercises and swimming brought home the reality of the shortfalls in my mobility and physical condition. Yet by that time I was able to feel happy about all of this because, for many years, I had not had the opportunity to do any of this.

When I got home I tried to remedy all my shortfalls. My hands were very painful whilst I was swimming, but I massaged them very often. Years later I could swim longer distances and this gave me so much joy. Slowly and gradually I was able to swim up to 1000 – 1300 metres. With the help of a doctor I changed my diet and

with regular exercise I lost almost 20 kilograms within a year. This made walking much easier for me.

I can thank my GP and psychiatrist for easing my isolation and for helping me to open up to the world again. This gave me the chance to live! Fortunately I met other fellow patients, who asked for help. “Guys, I can barely keep going myself,” I replied, but I could not say no. My conscience could not allow me to be indifferent and I started to organise things. This is how I found opportunities and self-confidence from knowing that I could be useful.

At first I took part in community services to help people, gritting my teeth because of my condition. My knees had to be drained from time to time, but I could not give up! There were dance events in our club. Slowly and gradually I started to take part in them. Many of us realised that dancing is an excellent overall physical exercise for the whole body so, even though we were not graceful, we were happy to dance. I recommend dancing as a group exercise for therapeutic purposes.

I am always grateful to the doctors, nurses and physiotherapists who, through their work and humanity, helped to improve my condition. I was able to thank them especially with my determination and

complaint-free behaviour. I was able to deserve their encouragement and trust.

“Dancing is an excellent physical exercise”

I exercise every morning on the carpet in the hope that today’s attempt will strengthen my chances for tomorrow. So by accepting pain there could be a chance for healing. When people saw me struggling while swimming or cycling, they asked me who I wanted to prove myself to. I said, “to myself”, because I became weak when I was young and, even now at the age of 67, I try to create something on which to base my old age.

Today, I can now say that with the treatments and the daily exercises I am able to walk with the steps of a grown-up man. My wish was granted. Even though it took about 30 years, it was worth it!

I am very grateful to all those who healed me. After I lost my health and my hope, they taught me to fight. I got strength and encouragement from them to achieve my hopes and wishes, and I am now able to do work that makes me and my environment happy.

I take every opportunity to encourage my fellow patients to realise that the person who can do the most for you is you! Many people remember and

acknowledge the extent by which my stamina has improved. Nowadays I am able to stand on my feet for hours whilst in the past I could only just stand for 10 – 20 minutes.

“Look for the opportunities where you can find happiness for yourself and for others,” I encourage them. I have learnt that if you help others, you also help yourself, because the love you give to others can heal you as well. I was able to do this and others can do it too.

It took a long time for regular exercise to become a well-established routine for me, but I realised the beneficial effect and it has improved my general wellbeing. All of this has given me the strength to feel that mental and emotional attempts are not enough to achieve your goals. I have had to do a lot for myself physically as well.

Humour and self-irony also made it easier for me to accept the difficulties in life. My hands and fingers will remain stiff for the rest of my life, but I tell those who ask me about them that they remain bent because I am constantly giving hugs. I try to keep order in my soul and thoughts, and spend time only with nice things. Every night I give thanks for all the many good things I have.

The second 33 years of my life, though full of struggle and pain, have been more joyful and valuable than the first 33 years I spent in good health. I wish this joy to all my fellow patients.



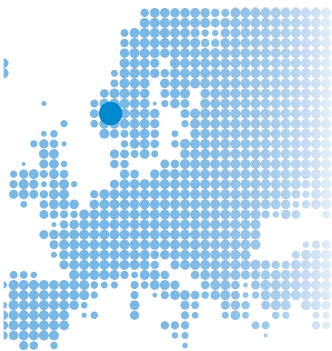
Janne Aasebø Johnsen



The angels along my way



Lillehammer Hospital: the place I began my journey back to health



**Janne Aasebø Johnsen
Norway**

My name is Janne Aasebø Johnsen. I am 47 years old, I live in Lillehammer and I am married with a grown-up daughter.

I came across the essay competition by chance on the Norwegian Rheumatism Association's website. It caught my attention because it talked about taking control of your own life. I feel I have real control of my illness now, but I have not got to where I am today without the help of friendly, supportive, attentive and skilled specialists. I decided to enter to explain just that.

I am a qualified teacher and have worked at Lillehammer School for 20 years. I have also written books for children and young people since 2004.

The angels along the way

2008

In the interval between sleep and waking, the pain takes hold of me.

Shoots arrows of torment into the small of my back.

Knife blades into my finger joints.

Cramps in my stomach.

Swollen, sore feet touch the floor.

I get up, even though I don't want to.

"My hands grip the banister. I pull myself upstairs"

Force myself to go to the bathroom.

Lean on the wall.

I manage to get to the bath.

Shower the worst of the pain away down the drain.

Get some clothes on.

Socks are the worst.

"In the midst of sleep I start to dread the next day"

Everything hurts.

My hands grip the banister.

I pull myself upstairs.

I take my painkillers.

The day begins, and it's fine.

It's fine.

I go to work.

I'm OK outside.

Afterwards I lie on the sofa until night comes and it's time to go to bed again.

Walking backwards, I go downstairs to escape from the day, and in the midst of sleep I start to dread the next day.

The illness came gradually and really broke out when my husband was away on an international operation in Afghanistan.

He came home, but the fight continued.

The stress in my body was so great.

2014

In the interval between sleep and waking, I find I am looking forward to getting up.

"I find I am looking forward to getting up"

My back is a bit sore because of the aqua aerobics I did yesterday.

My fingers are a bit stiff after writing yet another piece.



Angels are with me on every step of my journey

The pains in my stomach have eased.

I bounce into the bathroom.

Look forward to greeting the day.

Go upstairs, eat breakfast and take my cod liver oil capsules.

Work, lecture, amateur theatre, no end of clubs and writing projects.

The illness is dormant.

"Wellness came gradually"

Wellness came gradually, but I am absolutely certain I got better because of all the angels I met along the way from 2008 to 2014. The angels who put the illness to sleep.

The GP who quickly realised that I needed to be referred to the rheumatism hospital where I have been treated ever since. Always with respect and always taking me seriously.

The rheumatologist who understood that I needed to be admitted as soon as possible.

The nurse who talked to me and comforted me when I was afraid of the new drugs.

The physiotherapist who taught me the difference between good and bad pain.

The dietician who told me that people with rheumatism react to different foods.

The social worker who helped me to manage my life.

The occupational therapist who showed me finger exercises and equipment that could help me.

The activator who showed that creative work reduces stress.

The healthcare worker who taught me to relax with a hot compress.

The psychiatrist who helped me to understand that my illness was down to fear.

The physiotherapist who taught me to exercise effectively.

"I am certain I got better because of all the angels I met along the way"

The rheumatologist who saw that the illness had burnt itself out and said I could try to manage without drugs. Still, I could come back any time. They are still keeping an eye on me.

My employer who arranges my day and understands that I have to exercise every day.

The swimming group that included me.

My friend who gave me a CD of relaxation exercises.

My editor who let me go on writing.

It turned around slowly, but a crucial moment was when I realised that I had an illness where my body was attacking itself.

The first thing I did was to stop attacking myself.

What made me well?

The little conversations.

The looks.

The trust.

The suggestions.

The books.

The exercises.

... And all the angels along the way.



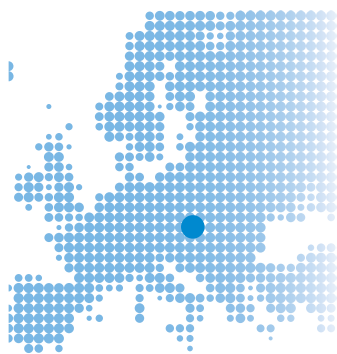
Veronika Cervenkova



Making dreams come true with beautiful view at Golden Gate Bridge



Enjoying time with my awesome parents and sister



Veronika Cervenkova Slovakia

My name is Veronika Cervenkova. I am a 20-year-old student studying at the University of Aberdeen in Scotland although my hometown is Bratislava in Slovakia. I am currently on a year-long exchange programme at the University of New Mexico in the USA.

I learned about the Stene Prize competition via an email from our youth rheumatoid Klub Klbik. I chose to participate because I have never thanked the people who have helped me with their incredible work enough.

Also, I think it is a great way to show people with similar problems that everything is possible even though the road might have many obstacles.

The long road to success

When I was two years old, I was diagnosed with one of the most severe forms of rheumatoid arthritis. In our society today it is normal that, as soon as you have a disability of any type, you are automatically put in a box labelled “invalid” wherever you go.

“You are automatically put in a box labelled ‘invalid’”

Our healthcare system is no exception. Many dreams and goals of disabled people are destroyed by doctors themselves who fail to support patients in their aspirations. The result is that patients expect always to be undervalued by others and this reinforces the idea that they will never achieve anything in life.

Exceptions prove the rule. I have also found people who not only supported me in my goals, but also provided me with substantial help in achieving them. I’m talking about my doctor – a rheumatologist – and my rehabilitation nurse.

When I was diagnosed with the disability, I spent a lot of time at what was then named the VÚRCH (Research Institute of Rheumatic Diseases) and is now the NÚRCH (National Institute of Rheumatic Diseases) in Piešťany, where I underwent examinations as well as very important procedures.

My doctor, who has remained my doctor to this day, told my parents that we had come “at the eleventh hour”. Had the disease been diagnosed later, it might have lead to permanent consequences, and even confinement to a wheelchair. Exercise had to be part of my daily schedule. My movements back then were very restricted, so I had to learn basic things from scratch: how to hold a spoon, how to walk properly.

My stays in Piešťany were always of limited duration, so I

needed to find a rehabilitation worker in Bratislava where I lived. What seemed like quite a simple task turned out to be very difficult and almost impossible in fact. No one was qualified to work with rheumatic diseases, and rehabilitation staff preferred not to have me on their hands. Every rehabilitation centre and department turned me away. We were reduced to tears.

Finally, fate brought me together with a rehabilitation nurse called Majka. She was willing to train me in spite of my very young age and my rheumatism. Majka had previously worked at NÚRCH as a rehabilitation nurse. When I met her, she was working at the Military Hospital as the chief nurse in the rehabilitation department.

“She helped me become a full person with a full life”

Majka took me under her wing and trained me and helped me in whatever way she could. After a while, as the



Making new friends while travelling around California



Welcoming New Year with friends



At breathtaking Lake Tahoe in California

demands of the school I was attending grew and I began to have less and less time, Majka would come to my home for rehabilitation sessions without the slightest hesitation. It was, therefore, possible for me to complete my rehabilitation exercises in peace and then to return to my studies.

It is impossible to place a value on the assistance and help that Majka has given me over the last 15 years. From a patient who narrowly escaped life in a wheelchair, she has made me into a person whose disability is invisible to others. Sometimes, the true value of a person's work can only be seen later on, when looking back at what was and comparing it with what is. The change is incredible, but it came at a high price in tears and pain for me, while demanding time, patience and strong nerves from Majka. She helped me become a full person with a full life.

I am achieving my goals today with a huge amount of help and support from my parents and my rheumatologist, who has never allowed me to withdraw into a shell where

everyone would feel sorry for me. The basis for the success of any disabled person is his or her approach to the disease and to life. This approach is initially formed, in particular, by the doctor and the people who surround you. My doctor never permitted me to feel sorry for myself; instead, she supported me in my hard work and studies.

As with any other disability, rheumatism partially restricts everyday life and it is, therefore, very important for me to study. I have learnt languages since childhood. I was accepted into an English bilingual high school and I wanted to study abroad for a year, as is common in such schools. Since my main language was English, I opted for the USA.

"The true value of a person's work can only be seen later"

My doctor disagreed at first, but conceded after the right arguments had been made.

At the time, my condition had long been stabilised, thanks in part to the biological treatment I underwent for several years. My stay in the US passed without incident, and my condition even improved a little. I was not at all sick, and I felt a lot better.

After returning home, I knew that I would complete secondary school here, but then go abroad again for university. All of my applications were addressed abroad and I was accepted by a number of universities in various countries. My doctor was less surprised by my choice of university than by my decision to study abroad while still at secondary school.

Today, I am studying in Scotland and the results of my studies have led to the selection of another exchange trip to the US. Since studying abroad, my healthcare results have improved, and I feel much better physically as well as mentally. My doctor continues to support me in fulfilling my dreams and goals. Despite my disability, I

am doing and studying what I want, where I want.

"I feel much better physically as well as mentally"

The kind of doctors who do not support patients in their activities – and who would not have allowed me to go anywhere – are still around. But I remain grateful for people such as Majka, who is sadly no longer with us, and my rheumatologist. They are proof that even if one person says "no" a hundred times, someone else will always come along who will go with you against the flow and give you the help and support you need.



Ana Vázquez



A picture of my son Li Zhang with me three months after adoption



Nothing is gonna stop me: finishing a presentation for an informative workshop



Ana Vázquez Spain

My name is Ana Vázquez Lojo. I am a 45-year-old mother of a child and I live in A Coruña in Galicia in Spain.

I am a trained speech therapist and occupational therapist, and I work in rehabilitation with deaf babies. Other roles I have include President of the League Reumatológica Galega and President of the Official College of speech therapists in Galicia.

Adaptability is man's way of surviving adversity

I was eight when I started getting pains, fevers, rashes and severe stiffness. Those images are blurred with playing games with my siblings, laughing and joking with my friends, and school homework.

I was admitted to hospital dozens of times and suffered many joint deformities and terrible pain, but I still remember my childhood filled with great happiness and excellent memories.

"I adapted better to change than other children"

The diagnosis came after a year of medical tests and discounting other diseases such as meningitis and leukaemia. It is the same disease I still have today: Still's disease.

My mother always told me that the disease had made me more intelligent, and maybe she was right. I was not more intelligent, but I did adapt better to change than other children and, later on, than other adults.

It also made me more prudent. My mother anticipated that my illness may prevent me from working with my hands or my body in general, so she suggested or rather persuaded me to train academically. I initially reached an agreement with her that I would study subjects that I found personally satisfying, even if they required physical work and carrying them out might be difficult for me later on.

I took an advanced-level course in anatomical pathology, then an advanced-level course in clinical laboratory science and then in childhood education. Later on I qualified in speech therapy and occupational therapy. All in all, I completed my studies at the age of 30 with some breaks in the middle for admissions to hospital and surgery. On many occasions I travelled to class by ambulance or sat exams from

the actual hospital. Today I work in the field of rehabilitation for children in early care.

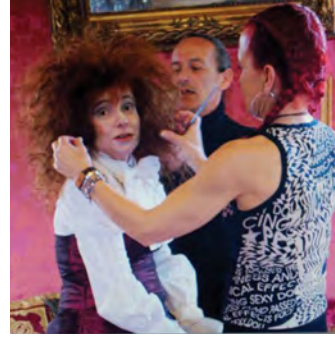
"I sat exams from the actual hospital"

I remember how cheeky I was, using my disabilities as an excuse to get out of household and family chores. As a little girl I would give an excuse for not being able to make the bed or go shopping. My mother, very cleverly, would say that she would give me more time, that I should make more trips to the supermarket with lighter bags or use the shopping trolley... Anything to let me lead a normal life.

Those were my first adaptations. They were very useful for my future adult life, as you will see later. This meant never giving in and using my head a lot. My illness was never in control of everything. I had frequent attacks, but they were less and less aggressive. My



Presenting our daily work at the Galician Rheumatic League to the Kings of Spain



For a photo of an exhibition of photographs on rheumatic disease



My life: winning photograph at the First National Contest, organised by the association of people with RMDs

adolescence and youth were crazy and unsettled. I went on a lot of journeys, always with adaptations and a lot of will power. One day I met the man who is now my husband, and I thought about motherhood.

It was from this point that Dr Genaro Graña, a great rheumatologist and a great person, had a leading role. At the Liga Reumatológica Galega (Association for Patients with Rheumatic Diseases) we call him "Papa Graña". He treats young people and children with rheumatic impairments and treats them with compassion.

As I was saying before, although the disease was unrelenting, it was also less aggressive. This was when I decided, with Dr Graña's agreement, to become pregnant. He was very frank with me. I needed to go for at least nine months without any immunosuppressant or biological treatments. We knew that it was difficult and indeed it was... IMPOSSIBLE.

I suffered attack after attack, with hospital stays that lasted more than a month. I was

admitted to hospital four times in total in one year. I became obsessed and asked for more time. Dr Graña and Dr Carlos Fernández asked me to stop and promised they'd help me with the international adoption process which, at that time, was starting to become very complicated for rheumatology patients.

The doctors' support and my husband's immortal phrase "Why do you want a child who you are not going to be able to hold in your arms or enjoy, and to live with the pain of the consequences" opened my eyes.

"The goal and objectives did not change"

Once again I was making the adaptations I was so used to, and the goal and objectives did not change. Just the approach. Motherhood is not about giving birth or carrying a child inside you, but about always carrying it

in your heart and your head. I was ready for this. The emotional support and advice from my rheumatologist were key factors. After 10 years of waiting, I have a son. Li Zhang is a two-year-old boy from China and is extraordinarily bright.

I went through some suitability tests, strict and tedious interviews heavily based on my abilities and on the deterioration of my disease. But I passed them with good marks. This was because of medical support, family support and my other abilities that are far superior to my physical abilities.

I would love to hear other stories like mine. I'm not expecting to win any competition. I would like to think that there could even be millions of stories such as this – about normalisation, about adaptability, about proactive patients and citizens willing to adapt to what is necessary to achieve what is necessary.

I am now 45. My character and my vitality have been the amazing combination that has

allowed me to be an actress, the President of the Liga Reumatológica Galega, the President of the Colegio Profesional de Logopedas de Galicia (Galician Speech Therapists' Association), a professional and a mother.

"My other abilities are superior to my physical abilities"

The chapters of my life are written by me. Not my illness. And Dr Graña and Dr Fernández are in all of those chapters.



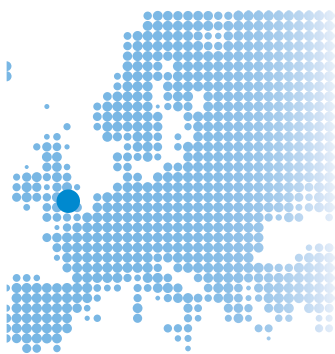
Francesca Leadlay



On Lake Como with my father



Playing the piano again



Francesca Leadlay United Kingdom

My name is Francesca Leadlay and I am 36 years old. I am originally from Cambridge but now live in London and share a flat with my sister. Formerly I was a policy advisor and press officer. I am currently on a career break but I am preparing to go back to part-time work.

I learned about the Stene Prize through the UK's National Rheumatoid Arthritis Society's website. I chose to enter because rheumatoid arthritis is a very complicated condition and everyone responds differently to medication.

I feel that the more information that people know – individuals, health professionals, scientific researchers – about this condition the better to improve the experience that others with rheumatoid arthritis may have.

Little milestones

Health professionals have played an invaluable role in supporting me and enabling me to live as independently as possible. During the four and a half years since being diagnosed with rheumatoid arthritis (RA), I have had a challenging time physically and emotionally because the first four drugs I tried gave me serious side effects (including an allergic reaction to one drug).

"I have had a challenging time physically and emotionally"

I experienced a turning point when my GP (family doctor) made me realise that avoiding taking a new RA drug for seven months was having a detrimental

effect on my body. He was rather blunt: "You have aggressive RA. Without medication, your joints could crumble". I needed to hear these words to get me back on track and begin new treatment.

"The risks of untreated RA were greater than the risks of taking drugs"

Around the same time, my rheumatologist did an ultrasound scan on my wrists and showed me that I had developed bone erosions during my self-imposed break from medication. She said that it was the worst scan (in terms of inflammation) that she had seen that month and that the risks of untreated RA were greater than the risks of taking RA drugs.

Her words, combined with my GP's advice, gave me the confidence to try sulfasalazine, followed by adalimumab and finally etanercept. Etanercept has begun to stabilise my RA. I have less pain and stiffness in my joints. Although I have not returned to work yet as my

fatigue levels are still high, I have been able to learn how to play the ukulele and have written a first draft of a children's book. I am also socialising more with friends than I did before commencing etanercept.

My NHS psychologist guided me through successful treatment for health anxiety and post-traumatic stress disorder, which I developed as a result of side effects from my RA medication. I had problems with insomnia and flashbacks for a long time. Then, after a year of therapy, my quality of life improved as I started getting a better night's sleep. Furthermore, thanks to my psychologist my feelings changed towards RA drugs and I started to see them as a positive antidote that would help me get better.

My specialist nurse has played a crucial role. Until earlier this year, despite having previously tried methotrexate and adalimumab by injection, I had never been able to self-inject. I was scared of the needle and because I was traumatised by previous bad experiences with hydroxychloroquine sulphate, sulfasalazine, methotrexate and adalimumab. I started the



At the Tower of London



Pruning roses

medication in January 2014 and, to begin with, my specialist nurse administered the drug.

Then, over several weeks, I learned to remove the grey lid (a tricky manoeuvre with swollen fingers), push out the air bubble and position the needle in my thigh at a 45 degree angle. However, my nurse still pushed the syringe plunger to complete the injection.

“I felt an amazing sense of achievement”

On 27 March 2014 I managed to do the whole procedure myself – by now it was my 12th dose of etanercept. I even pushed the plunger and removed the syringe. It was not as bad as I thought it would be. It stung a bit, but not too much. I felt an amazing sense of achievement as well as relief. This was a huge milestone.

After achieving this personal goal, I continued to self-inject in front of the nurse for a few more weeks until I felt confident enough to complete the procedure at home. It became easier with practice and now I save a lot of time by not having

to go to the hospital twice each week, as well as gaining independence and control of my life.

I think that diagnosis times could be improved in the UK, particularly for people with seronegative inflammatory arthritis. I believe that when I was diagnosed, in August 2010, I had already been living with rheumatoid arthritis for some time. I had early morning stiffness in my hands and painful joints for a number of months. As my inflammatory blood markers were negative, it was only after I had had an MRI on my hands that I was told I had RA.

I understand from reading other people’s stories through an online support group for UK patients with RA that they have also experienced a long waiting time to receive a diagnosis. A faster diagnosis would also mean that people with RA start treatment sooner and potentially get their RA controlled more quickly.

I think another area for improvement is that healthcare professionals should treat fatigue as seriously as other symptoms like pain and swollen joints. I believe that healthcare professionals should integrate measuring fatigue amongst RA

patients into their overall approach to managing the disease. Although symptoms such as joint stiffness, swelling and extreme pain are equally important, I feel that chronic fatigue has been overlooked. This hidden aspect of the condition can be just as disabling (or even more so) than joint pain, stiffness and swelling.

If healthcare professionals placed more emphasis on chronic fatigue then I think that employers would also have a better understanding of the need to make reasonable adjustments in line with the UK’s Equality Act. This would ensure that employees with RA have flexible working conditions and are not discriminated against in the workplace.

“I feel that chronic fatigue has been overlooked”

I think an ideal relationship between health professionals and people with RMDs looks like the one that I have with my healthcare team. I feel very lucky

that I have access to all the health professionals that I need, most of all a dedicated specialist nurse and my rheumatologist. When I am uncertain about what to do (for example, when I have a lung infection and need to know how soon I can restart etanercept after finishing the course of antibiotics), my nurse is easily reachable and gives good, constructive advice.

Both my rheumatologist and nurse monitor my condition regularly, including taking my Disease Activity Score, and through blood tests to check that my neutrophils are not too low. If they are, I stop etanercept for a while and resume it if the next blood test shows the neutrophils have returned to normal. My rheumatologist performs an ultrasound every few months to assess the current level of inflammation in my hands and wrists, as well as my feet.

From experience, good communication and being prepared for every appointment by writing down key points that I want to discuss relating to symptoms and treatment are essential to an ideal relationship between health professionals and people with RMDs.



Ingrid Vandepaer, Belgium Flanders



Annelies Vanhooland, Belgium Wallonia



Saara Kantanen, Finland



Florence Chatain, France

Meet the other essayists

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 2015 competition

Belgium Flanders

Ingrid Vandepaer,
Kessel-Lo, Belgium Flanders

“And how are you, ma’am?” asks the young rheumatologist.

“As with the traffic on the roads in Flanders, doctor.”

He gives me a puzzled look.

“Yes, I have had to take a diversion, but it has turned out OK.”

“Mmmm. And how do you feel now, ma’am?”

“I will just outline how it was. Have you ever tried getting across a busy intersection on a rainy morning, doctor? You feel tired, your left eye stays closed because that morning you applied some ointment there and you limp as you walk. Your left ankle hurts and your feet are swollen. The traffic lights are not working that morning and everyone is in a rush. You are there. Vulnerable and quiet. Everything and everyone moves around you. And you wonder how you got to the other side safely. Did you ever experience that, doctor?”

Belgium Wallonia

Annelies Vanhooland,
Namur, Belgium Wallonia

Like everyone in this world, I have my personal heroes. The first “hero” that I recall is my former paediatrician and haematologist, Prof David Tueslinckx.

I really liked my consultations with him and, as a child, my ambition was to follow his profession. Then, there was Prof Boutsen in whom I have – and will always have – a blind confidence. It is rare to find a doctor like him and I even think that you need to make him come back several times during Saturday night in hospital just to be sure (wink wink!).

Prof Chantal Doyen, haematologist, also impressed me with her strict approach and her knowledge of my file, even when she was no longer following my case. These three doctors – I would entrust them with my life and I love amazing them. Just like the rest!

Finland

Saara Kantanen,
Lahti, Finland

Pain, the familiar sensation from way back. You were there even when I was just a little girl. The small town country doctor explained you off as growing pains. When during springs and autumns other children cavorted in the fields and woods, I sat tightly at home both arms in arm slings, letting the imagination run wild.

I travelled around the world – I was a famous ballerina or a figure skater, a mountaineer or an explorer. My dreams had wings, even though I was not allowed to move about.

I grew up; you were still present. I was not growing in height anymore, but still you were a constant companion. I could not tolerate even to be touched, and I was considered a hypochondriac. Surely such a young person could not be severely ill?

France

Florence Chatain, Sainte Genevieve des Bois, France

I restore old books, engravings and drawings... I am starting to organise myself in order to get to work with my hand-supporting orthotics. I take pains not to get irritated by the clumsiness of my movements, to work with the tips of the fingers that are still OK.

This is because I want to ask for some adjustments in my work, but not a change of job, as was the advice of my GP.

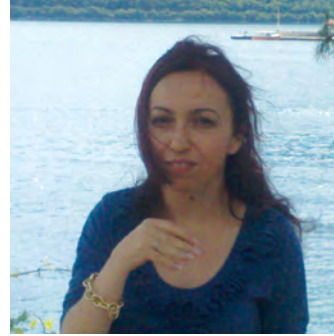
I want to find out about my rights, my disease, the possible remedies, and to get some support from associations.



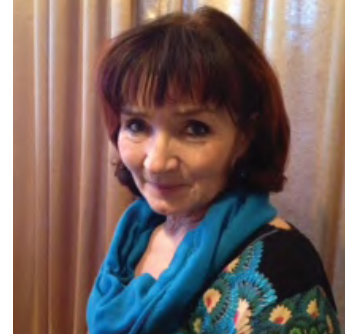
Arndís Þórarinsdóttir, Iceland



Siobhan Jones, Ireland



Ljiljana Lazovic, Montenegro



Elżbieta Śliwińska, Poland

Iceland

Arndís Þórarinsdóttir,
Kópavogur, Iceland

“No one but me understands how ill you are,” said my rheumatologist to me. As a rheumatologist, he had seen it all. What he wanted to say is that no member of my family, no employer or colleague of mine, could possibly understand what it means to always be ill. What it means to always feel tired. And how it feels to witness your personality changing.

That’s exactly what happened to me: I became a completely different woman.

Rheumatism is a severe disease and an invisible one. You will hear many people telling you that it is not such a big deal. But you mustn’t listen to them. Listen only to that voice inside your head. When I look back, what I remember most is the voice of a rheumatologist who not only silenced the voices of all the other doctors, but also one who gave me direction and confidence.

Ireland

Siobhan Jones,
Galway, Ireland

I found counselling extremely beneficial – that journey began in 2007. At that time I had convinced myself that in six months I would be back to “normal”. After a lot of work with my counsellor, I realised that I’m never going to be “normal” again.

Today, I embrace my differences and feel that I’m constantly learning new ways to deal with fibromyalgia and chronic pain. I believe counselling enabled me to set out goals for my future.

Now I feel like I have a solid team of health professionals working with me to help me live the best life I can, in spite of my condition. I now have great hope for my future.

Montenegro

Ljiljana Lazovic,
Podgorica, Montenegro

As a young girl, I became acquainted with arthritis against my will. I don’t know if this was fate or if it was God-given. I only know that arthritis has given me a permanent disability and that life has become a greater battle for me than for others.

I’ve had to face various hurdles. There has been suffering, tears, despair. But somehow I have found the strength to overcome all of this as I have loved life. I’ve had an invisible power within me that has always led me forward and never allowed me to give up.

Poland

Elżbieta Śliwińska,
Gdynia, Poland

Patients must know the basic facts about the disease. They must be aware of what it involves, how to deal with it, how to be rehabilitated and how to reorganise their lives so that, despite the illness, they can live as well as possible. In addition, there is no point in hiding the disease because, all of a sudden, someone can recommend a physiotherapist, someone else will tell you about a diet... And in this way, other doors of how to deal with the illness just open up.

With our disease, rehabilitation is very important. We can read about this ourselves but, especially at the beginning, nothing can replace a physiotherapist who will show us how to perform exercises in a way that will help and not harm us.



Ana Paula dos Santos Nunes, Portugal



Corina-Eugenia Cristea, Romania



Katarina Stojkovic, Serbia



Adam Hedengren, Sweden

Meet the other essayists

Portugal

Ana Paula dos Santos Nunes,
Azeitão, Portugal

Nanda always believed that life was beautiful, that everything was perfect and that she was practically the same as everyone else – we all have differences and limitations in one way or another. She managed to do everything that they did and, if she did not succeed, she adapted and got there in the end! At no time did she feel diminished by having arthritis and did everything she could to achieve what others achieved.

Nanda is a happy person because she knows that it is not the arthritis which has her, but she who has the arthritis. The arthritis only goes as far as she and the health professionals let it, since she is not losing her will, her faith and her determination. Nor will she lose them because she knows that, even with the difficulties, it is worth keeping charge of your life.

Romania

Corina-Eugenia Cristea,
Bucharest, Romania

My entire life had been turned upside down. Filled with sadness and pain, wearing a grimace for a smile and demoralised, I felt that my life had lost its meaning. My soul was empty and small, yet as heavy as a millstone. Things had changed and I had to accept my new situation.

I did two things that got me back on track: I resumed my studies and started a rehabilitation programme at one of the best specialist hospitals in the country.

By changing my attitude (I replaced resignation with proactiveness), I became able to communicate better with my entire body and manage my mood and bouts of pain. I started to like myself again and left behind all guilt and sadness. I learnt to love myself despite the spondylitis and I was able to let others do so too.

Serbia

Katarina Stojkovic,
Niš, Serbia

It was hard balancing the demands of university study with the needs for my arthritis. Fortunately, the medical staff were always there to help me. They had sympathy for me and understood my commitments. I was in pain, but I fought like a lioness and managed to pass all my exams in time.

I'm now a 28-year-old high school teacher working at a school, but I don't have permanent work. Working with teenagers can be tough. I still have to balance my work with seeing doctors for check-ups and taking medication.

No one at work knows about my illness. I can't tell any of my superiors because I'm worried they won't understand my situation and I'll be left without the job I find fulfilling and satisfying.

Sweden

Adam Hedengren,
Stockholm, Sweden

I grope around in the memories of my illness. The images merge together and I find it hard to categorise and rank the painful periods in my life. Maybe that says something about healthcare in Sweden. Maybe it's a sign that most things went OK. Or perhaps I simply learned to live with the pain.

With the support of my doctors, I managed to live well despite the rheumatic condition. We did a lot of things right. But we did not see the whole picture, and I personally did too little to discover the possibilities that were out there.

The responsibility for more humanitarian treatment rests with both the individual and with the hospital and society as a whole. By developing our views of health and medical care, we can give thousands of rheumatism sufferers a better chance of living with the pain.



Elodie Ribeiro, Switzerland



Carole Gagné, Canada

Switzerland

Elodie Ribeiro,
Geneva, Switzerland

I rubbed shoulders with this world of doctors and health professionals for a year and I must say that it is never easy to get used to a new culture. But I learned to stand up for myself and take a stance, to make myself and my beliefs heard, but also to obey in the full knowledge of the reasons. It is difficult to hear that you are not wanted somewhere, because you take up time and because your case is complex. You feel rejected when you need help and when you are at the right place.

Enriched by my trek along this road strewn with obstacles, today I can say to the doctors and care workers that they should learn to talk among themselves. It's essential when a patient has several doctors and your case is complex and long term. Each person is unique, which is something they should not forget.

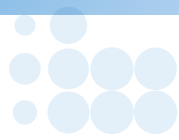
Canada

**The Edgar Stene Prize
has reached out beyond
Europe...**

Carole Gagné,
Québec, Canada

A new life and I am presented with the opportunity to take it in hand, to take control of it. Along the way, I was privileged to meet some good people at the right time, who gave me the keys to open doors to exploration, study and understanding.

... I am sincerely convinced that a new life for me is about to begin. The changes in my body and my head are taking place gradually, and even my face is blossoming. A new Carole is emerging. I see her as being in better form than she has ever been, just a few months ago... with travel plans, work, physical exercise and presenting a good impression of myself for the people that I love.



eular

EULAR Secretariat

Maria Batziou, Birte Glüsing, Florian Klett

Seestrasse 240, 8802 Kilchberg, Switzerland

Tel: +30 6946232776, +49 228 9621283 and +41 44 7163035

Email: Maria.Batziou@eular.org, Birte.Gluesing@eular.org and

Florian.Klett@eular.org

Website: www.eular.org

[◀ CONTENTS](#)

[◀ BACK](#)