Being a person with a rheumatic or musculoskeletal disease – How my voluntary work benefits me

Winning essay from Bulgaria
HRISTINA BANKOVA
One step at a time

Second place essay from the Netherlands
SANDER OTTER
A steady wind to Pampus

Third place essay from Romania
VASILE PRUNILA
The joy of giving
THE JOY OF VOLUNTEERING

Many people living with a rheumatic and musculoskeletal disease (RMD) choose to become volunteers. People’s motivation can vary. Some want to give something back to the community while others want to learn new skills, to share personal experience and knowledge or to meet new people.

The joy of volunteering is that you can decide how much time or commitment you are able to give. It doesn’t have to take over your life, rather it should enhance it. The joy of volunteering is that you can decide how much time or commitment you are able to give. It doesn’t have to take over your life, rather it should enhance it.

This year’s Edgar Stene Prize competition on the theme of “Being a person with a rheumatic or musculoskeletal disease – How my voluntary work benefits me” has allowed people to reflect on what volunteering means to them. To read how so many people give so much of themselves to help others is inspiring. Many people within the EULAR family volunteer their time. People’s dedication never ceases to amaze us. There are at least 120 million people with RMDs in Europe: the EULAR network is motivated by making a difference for all of them. We give our time to run organisations, to share our experiences of living with the condition, to raise awareness of the need for early diagnosis and the right treatment at the right time. Working together, we continue to have great success.

It is our pleasure to present this year’s winning essay by Hristina Bankova from Bulgaria. Her experiences demonstrate the range of benefits volunteering can bring.

We would like to thank the Edgar Stene Prize Jury who all volunteered their time to read through many essays from across Europe. We are delighted to share our top three with you in this special booklet. Please share this booklet widely. The more we raise awareness about RMDs, the more positive change we can bring.

Dr. Elsa Mateus
Chair of the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (PARE)

First awarded in June 1975 during the EULAR Congress in Finland’s capital city, Helsinki, 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).

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

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.

Preparations to create the Edgar Stene Prize followed the establishment of a new EULAR Constitution at the organisation’s General Assembly in Paris on 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 healthcare, research, fundraising, patient care, education, public relations, etc.”

* 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).
Every year, the Edgar Stene Prize is awarded to the person with a rheumatic or musculoskeletal disease (RMD) submitting the best essay describing their individual experience of living with their condition. Competition details are distributed to EULAR PARE member organisations so they can run the competition nationally. Member organisations select the best entry from their country to submit to the EULAR Secretariat for judging by the Edgar Stene Prize Jury.

For 2020, entry was open to people with an RMD aged 18 years and over. Entries could be submitted in the author’s native language as EULAR arranges to translate national winning entries into English.

The winner of the Edgar Stene Prize is announced by the EULAR Standing Committee of PARE on the EULAR website, via social media and in its newsletter. The value of the first prize is EUR 1,000. The second-best essay is awarded EUR 700 while the third ranking essay receives EUR 300.

The deadline for each national competition is set individually by the national organisations. For details for 2021, get in touch with your respective national EULAR member organisation of PARE: https://www.eular.org/eular_pare_organisations.cfm
I am a 47-year-old perpetual optimist – perhaps an idealist. I have lived in Sofia, the capital of Bulgaria, since I was born. I’m married, with a grown up son. I started my career in 1995 working in the air import department of a logistics company. Since then I have had a passion for logistics and transportation. Currently, I’m a supervisor in a logistics provider company with offices in Romania and Hungary, and its headquarters in Bulgaria.

I love reading, cooking, travelling and enjoying good food with family and friends. I am a philologist (someone who studies the history of languages) but I have never worked in this field.

I learned about the theme of the 2020 Edgar Stene Prize competition from an e-mail distributed to the members of the Bulgarian Organisation for Patients with Rheumatic Diseases (BOPRD) and felt: “This is my topic”.

I believe volunteering brings fun and fulfillment to my life which means a lot to me. I was a volunteer with BOPRD even before I was diagnosed with scleroderma because I believe that in some way – small or large – volunteering is a way of doing good. Through my actions and involvement I’m benefiting others on one hand, as well as myself on the other.
ONE STEP AT A TIME

It’s May 2013. I am wearing a T-shirt with the logo “World Lupus Day.”

I am holding a stack of the same T-shirts, plus pens and flyers in my hands.

I am standing in the centre of Sofia accompanied by four more people wearing the same T-shirts.

I don’t have lupus.

And I don’t even know anyone who has the disease.

I have learned the basics about the disease so I can give an explanation should someone ask me while I am here telling people that we are running a lupus awareness-raising campaign.

Why am I here? I want to support the handful of people who created the Bulgarian Organisation for Patients with Rheumatic Diseases (BOPRD) with so much passion, enthusiasm and effort some three years ago.

On that particular day in Sofia, I still don’t know that I have a rheumatic disease myself. But I do know that something good, something beneficial is happening. People — occasional passers-by — are told that there is a category of diseases called rheumatic diseases.

Rheumatic diseases are not as well-known as diabetes or hypertension. There are often no visible symptoms to suggest that you are facing a person with a serious chronic illness. At that time in May 2013, little is known about these diseases in Bulgaria because the organisation is still very young. But the organisation will grow and develop to become what it is today — a trusted partner of doctors and a forum for patients.

“Every encounter makes me feel more motivated”

Still, in May 2013, we stop passers-by to give them a flyer and a T-shirt, and to explain what we are doing and why we are doing it... Why we should talk about lupus and rheumatic diseases.

I feel I am making a difference.

My personal goal is to attract the attention of as many passers-by as possible who will listen to me rather than simply pick up the flyer and continue on their way.

Every encounter makes me feel more and more motivated and satisfied. I am proud of myself. I am sure you all know this great inner sense of personal satisfaction that inflates you just like a balloon and you tell yourself: “I can do it! I am doing it! And I am good at it!”.

I already know that this is “my” cause and that, from now on, I will give my full support to BOPRD and to this cause — the cause of people with rheumatic diseases whose voice has to be heard.

“Everything in life happens for a reason”

Years will pass by and I will keep on handing out many more flyers. I will talk to many more people. Not only about the diseases, but also about early diagnosis, modern treatment, rehabilitation — about any topic we want to focus on in our BOPRD campaigns.

I will educate myself by reading much more about these diseases. I will meet other volunteers within the organisation, some of whom will later become close friends. I will be diagnosed myself — with scleroderma. Everything in life happens for a reason.

I will also have the opportunity to participate in the EULAR PARE patient conferences, after which I will always feel more motivated, more hopeful and more knowledgeable – confident that I have to spread this knowledge with the aspiration and conviction that I am doing something meaningful.

I will go to work and, at the right moment, I will tell my colleagues about rheumatic diseases. My colleagues are certainly among the most competent on the subject, bearing in mind that none of them has a rheumatic disease. They are just the kind of people who are open to new experiences, who are understanding and supportive.

“My reward comes from meeting new and interesting people”

Since that day in May 2013, this flame has been burning inside of me.

I still enjoy “working” as a volunteer at BOPRD. I don’t get paid, but my reward comes from meeting new and interesting people, building friendships, having fun, as well as gaining knowledge, wisdom, experience, trust and a sense of meaning.

Being a volunteer is just like being a hero — not the type of hero who shoots and kills the bad guys. But rather the type of hero who makes the world a better place, one step at a time.
I was a volunteer with the Dutch Lupus Association for a long time, where I tried to increase awareness of antiphospholipid syndrome. Unfortunately, illness forced me to give up this voluntary work and I am looking for a new challenge. There is still a lack of clarity and knowledge about antiphospholipid syndrome although many doctors, professors and patient associations work very hard to change that.

I am 53 years old and my hobby is spending time on my sailing boat, which is where my Edgar Stene Prize story began. By participating in this competition, I hope that I can make a positive contribution by increasing awareness of the possibilities offered by voluntary work.

I would also like to use the EULAR international platform, by means of this beautiful, powerful and true story, to draw extra attention to antiphospholipid syndrome and the work that is being done on it.
A STEADY WIND TO PAMPUS

The difference you can make as a volunteer – in everything you do – became clear to me during a little experience I had on the IJsselmeer. Now I know sailing on the IJsselmeer sounds spectacular, but I’m a real go-getter by nature – once I’ve set my course and trimmed my sails correctly, I find that boredom quickly sets in.

When I’m done with checking the radio and GPS, I go in search of something else to do. With all the modern technology we have today, I can even check my e-mails out in the middle of the lake. And, on that particular day, I read an e-mail containing a cry of despair.

It came from a woman in the 30th week of her pregnancy. The doctors couldn’t agree on how to help her through the remainder of her pregnancy, except for that a baby was supposed to be born at the end of it.

“I read an e-mail containing a cry of despair”

The woman had been diagnosed with the rheumatic condition antiphospholipid syndrome and, back then, all doctors did was whatever they thought might be a good idea. They really did just do whatever occurred to them... but what did she actually need? The answer was clear: someone with the knowledge and experience to help her bring her baby into the world.

Almost at once, the name of a gynaecologist came to mind. She had recently given a lecture and, by coincidence, I had her private e-mail address. Under a steady wind to Pampus, I explained the problem and, before I’d sailed two miles, she replied saying that the expectant mother would be welcome to come to the university hospital the next day. The gynaecologist was willing to see her through the pregnancy in person.

It goes without saying that I passed the good news on to the expectant mother, and wrote back later to ask if the pregnancy was going well. After that I forgot all about it in the hustle and bustle of my daily life.

I gained many skills during my career, but I had never known exactly what I wanted to be when I was growing up. When I turned out to have a chronic illness and was declared unfit for work, doors slowly started opening for me showing opportunities I had never suspected existed.

“Doors slowly started opening for me”

It began with the discovery of the difference between an outlying hospital and an academic treatment centre with trainee doctors and professors. I joined a patient association where I turned out to have a real knack for networking. I was the über-volunteer everywhere I went, even taking a real “Uber” at times.

For honesty’s sake I should add that, as well as reimbursing all my expenses, my voluntary organisation gave me fantastic support in the form of knowledge gained through courses to improve my skills. It was good for our organisation and for my personal development as well.

Back when I was working on the patient association’s website, I was allowed to take courses on “Writing for the web” and “Help Google find your website”. When I found myself behind a microphone on more than one occasion, the course “Present yourself” was waiting in the wings. These are all skills that leave me wondering now why I didn’t learn them at primary school. Ultimately, I was promoted to the top management of the association, and I took the course “Vergadertijger” or “Meetings for champions”.

As a member of the board, I clearly had obligations beyond selflessly advising and representing our members and their interests. While I was in that role, I had to chair a meeting about antiphospholipid syndrome. As a patient with the same syndrome, I had, of course, planned to attend the meeting about my condition. But now I found my own name up in lights on our website.

“It reminds me how important my work as a volunteer is”

Shortly before I walked into the hall, I was approached by a young woman with a baby in a sling. She wanted to thank me for putting her in touch with her gynaecologist on a lovely afternoon last spring in the middle of the lake.

I have bumped into the woman regularly since then. I’ve forgotten the baby’s name now – and even the woman’s name – but it still reminds me of how important my work as a volunteer is, how big some little things can be and how a little effort sometimes goes a long way.

This has added value to my life in the sense of being able to believe – as a human being – in a meaningful existence with a chronic disease. Not just for myself, but for others as well.

Sometimes people ask me where I get the strength to keep working so hard as a volunteer with all my health problems and difficulties. And then I love to tell them once again about that day I was sailing towards the Markermeer.
I am a 45-year-old freelance photographer now living in the town of Focșani in Romania. I was born in Satu Mare, a city located in the North-West of Romania. At an early age I was diagnosed with scoliosis, a condition that has always imposed certain limitations on me.

In my adolescence I discovered photographic art, thanks to a friend. It has continued to be my great passion until now, although I have had different occupations and, over time, I have also flirted with web design.

The desire to involve myself and to try to help others around me came 10 years ago when I created an online platform for disabled people. About nine years ago, I met Iuliana. She became my wife and I moved to the other end of the country to be with her. Since then we have been fighting together to remove the barriers disabled people face in their lives.

I learned about the Edgar Stene Prize competition from other members of LRR – the Romanian League Against Rheumatism.
I’m not really sure where these last ten years have gone...

Ten years during which I have learned to be an administrator, a co-ordinator, a web designer, a driver, a photographer, a cameraman, a video editor... Ten years during which I have made friends and have learned to give and to receive.

Voluntary work is not just an unpaid activity; it is a lifestyle. It is the joy of giving!

Ten years ago, the main problem facing disabled people in Romania was an inaccessible environment. There was an absence of information (about legislation, medical news etc.) that could have improved people’s quality of life and reduced their isolation in their own homes.

It is very important to know your rights because, if you know them, you are able to claim them, defend them and try to find solutions to the problems you face. It is also important to learn how other people have handled similar situations – rights violation, health problems.

“Loneliness can sometimes be more painful than disability itself”

I was passionate about web design and, when I was myself diagnosed with scoliosis, I told myself that I could try to change something in this regard. So I created the online platform DizAbil.eu to enable disabled people to get to know their rights, to find medical news and inspirational positive examples, as well as negative examples around them. This would enable them to communicate and seek solutions to the problems they face together. At the same time, they could connect with friends because loneliness can sometimes be more painful than disability itself.

Despite the fact that I put part of my soul into this project, I never dreamt that it would reach so many people in difficulty. Over the past ten years, the online platform has reached more than 400 members from all across the country.

Even though I started this “adventure” ten years ago all on my own, my effort has been rewarded more than I could ever have hoped. Indeed, the DizAbil.Eu project has brought me not only friends but a family. Just one year after launching the platform for disabled people, I met Iuliana while I was looking for a team to provide me with the necessary support to co-ordinate it. She was a blogger and support group co-ordinator for people with rheumatoid arthritis. Just two years later she became my wife. Thus DizAbil.Eu brought together two dreamers who lived 700km from each other and who, probably, would not have had many opportunities to meet and start out on the same road together.

“We thought we should do more”

My wife and I have become partners not only in our daily lives, but also in all the voluntary activities that we have initiated.

Seven years ago we thought that we should do more. We decided to move beyond the virtual environment and organise meetings with the members of the platform in Vrancea, the county we live in. Thus, we created the Dizabil.Eu Vrancea Civic Group which soon became a big family, campaigning for accessibility according to EU rules regarding public institutions, sidewalks and public areas in general.

We meet, we set common goals and strategies for achieving them. We co-ordinate community-organisation workshops, we draw up petitions aimed at authorities or economic agents that violate the law protecting and promoting the rights of disabled people. We visit cultural places and we create campaigns to enhance public awareness. We use all the means at our disposal to convince local authorities to take necessary measures to make our localities “friendly” for disabled people.

The most recent campaign launched by the DizAbil.Eu Vrancea Group is called “We want Focșani without barriers”.

Regardless of the fact that disabled people are sometimes perceived differently, with only their disability being noticed, disabled people are more than that. They are people who have their own normality. They have many weaknesses, sometimes many complexes, but they have as many qualities as a healthy person – even if people often fail to recognise their value in benefitting their community. We try to stimulate disabled people to showcase their skills, even by involving them in voluntary work.

Voluntary work takes time and effort, but without these voluntary activities to support disabled people I would feel much poorer. These activities have given me a wife and many friends. Thanks to my desire to make a greater contribution to the activities of the group – besides administrating the online platform – sometimes I am a driver, bringing the members who have difficulty moving to meetings. I also take pictures and/or film our activities. Like me, each member of the group has the opportunity to showcase their abilities or to discover new skills as a way of supporting the group.

“Every change brings immense joy and motivates you to go further”

It is not easy to make changes in our local communities or to change the way people think. But every change, however small it may be, brings you immense joy and motivates you to go even further. In addition, it makes you forget about the physical pain, the failures and the fatigue caused by your illnesses or effort.

As far as I am concerned, voluntary work makes me feel useful and I believe that this is my mission. I’m doing exactly what I like doing!

I am learning new things all the time, I get to meet beautiful people and, more than that, I am discovering myself. I am more than I would have been if I had been healthy and hadn’t felt the need to get involved to change something in other people’s lives, as well as in my own.

These activities do not bring me any material gain, but helping people in difficulty brings a richness of the soul that can hardly be quantified.
Each year, a panel of people with experience or knowledge of rheumatic and musculoskeletal diseases (RMDs) has the honour of judging the Edgar Stene Prize competition. We welcome five judges who represent the three pillars of EULAR, and who come from different countries across Europe. Among them is the leader of the 2020 Jury, Jeanette Andersen.

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.

**Dr. Elsa Mateus**
Chair of the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (PARE)

**Dieter Wiek**
EULAR Vice President, representing PARE

**Jeanette Andersen**
Leader of this year’s Edgar Stene Prize Jury, PARE Board Member from Denmark

**Prof. Daniel Aletaha**
EULAR Treasurer from Austria

**Beth Dillon**
EULAR Young PARE Board Member from the United Kingdom

**Erika Mosor**
Chair of the EULAR Health Professionals in Rheumatology Scientific Sub-committee from Austria

**Tom Erik Torbergsen**
Board Member of the Norwegian League Against Rheumatism

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**JOIN A EUROPEAN FAMILY**

We are the European organisation representing the people with arthritis/rheumatism, health professionals (HPR) and scientific societies of rheumatology of all the European nations.

We aim to reduce the burden of rheumatic diseases on the individual and society, and to improve the treatment, prevention and rehabilitation of musculoskeletal diseases.

We foster excellence in education and research in the field of rheumatology. We promote the translation of research advances into daily care and fights for the recognition of the needs of people with musculoskeletal diseases by the governing bodies in Europe.

EULAR is a non-profit scientific and educational association according to Swiss law; it is recognised as a tax-exempt charity by the tax authorities of the Canton of Zurich, Switzerland.

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Albania, Armenia, Austria, Belarus, Belgium, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Latvia, Lebanon, Lithuania, North Macedonia, Malta, Moldavia, Montenegro, the Netherlands, Norway, Poland, Portugal, Romania, Russian Federation, San Marino, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey, Ukraine, United Kingdom.
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World Arthritis Day
Young people with arthritis

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Abstract awards
Honorary membership
Meritorious service award
Stene Prize

EMEUNET – EULAR Young Generation

EDGAR STENE PRIZE BOOKLET 2020

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