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.

Member organisations select the best entry from their country to submit to the EULAR Secretariat for judging by the Edgar Stene Prize Jury. Meet and get to know more about the 2020 Jury here!
“I started volunteering when I was 15 years old. I wanted to be a journalist, so I applied to gain some experience and have access to training at a local radio station. Over time, I was also a volunteer in folklore and cultural groups, and parents’ associations.

It was only after winning the national competition for the 2007 Edgar Stene Prize that I became a volunteer with the Portuguese League Against Rheumatic Diseases and with PARE. During several periods when I faced unemployment and disability, being a volunteer kept me busy and reinforced my sense of being able to make a meaningful contribution to society.

The benefits of voluntary work for me are the knowledge and experience gained, the network of people I come across and the chance to develop different skills. Engaging in volunteering makes me forget my own condition and problems. It also provides me with greater insights that are useful for me as a patient, and for my organisation and all the people it represents.

Being a volunteer has always been very enriching for me, and I trust my contribution can also be meaningful to others.”

ELSA MATEUS
CHAIR OF THE EULAR STANDING COMMITTEE OF PARE
“My voluntary work began more than 30 years ago. There was a small group of people with rheumatoid arthritis (RA) and ankylosing spondylitis (AS) in our town, and a few of us activists felt we needed more disease-specific information and group physiotherapy. So we invited rheumatologists, GPs and pharmacists to our meetings which we announced in the local newspapers and made open to the public. More and more people joined our meetings and group therapies. Our local organisation grew quickly. And so the work for those few volunteers became more and more demanding.

People’s motives for doing voluntary work are diverse – such as coping with your own problems, communicating with others and feeling understood. Voluntary work means investing a lot of time and energy in providing support for others, but it also means great gains for the volunteer. You acquire skills and knowledge about self-management, about your rights in the social system, and you experience recognition and appreciation. These competition essays show how voluntary work can be a great benefit to the individual.”

DIETER WIEK
EULAR VICE PRESIDENT, REPRESENTING PARE
It has been a real honour to be part of the Edgar Stene Prize Jury for the first time. I found the stories highly inspiring. They get across how unselfish voluntary work really empowers so many of those people with rheumatic and musculoskeletal diseases (RMDs) who give up their time to help others and to raise awareness of a range of diseases so few people understand or empathise with.

A message I have taken from the essays is that, sometimes, you ‘simply need to do things’ to make them happen.

DANIEL ALETAHA
EULAR TREASURER
FROM AUSTRIA
“The Edgar Stene Prize competition is a very good way of highlighting the life of people with rheumatic and musculoskeletal diseases (RMDs). The authors provide their points of view and we readers get a small glimpse into the lives of people living with an RMD, learning about issues we didn’t know about. I am in awe of the courage and strength shown in the stories. I believe this year’s topic, on the voluntary work people with RMDs are involved with, can serve as great inspiration to other people living with RMDs. They help to highlight how you can reclaim control over your life and they act as a testimony to the rest of society on the importance of taking matters into your own hands.”

JEANETTE ANDERSEN

LEADER OF THIS YEAR’S EDGAR STENE PRIZE JURY, PARE BOARD MEMBER FROM DENMARK
“I am a 19-year-old student from Glasgow in the UK, and I have been involved with the Young PARE working group since April 2019. The Edgar Stene Prize is a brilliant opportunity for people across Europe to discuss and raise a light on a certain issue. The act of writing can be an immensely empowering experience, so having the platform to encourage people to do this is a fantastic opportunity.

The voluntary work that people with rheumatic and musculoskeletal diseases (RMDs) are involved with is incredibly valuable. Not only does voluntary work benefit those it is aimed at, it also allows those with RMDs to connect with those in similar situations and provides a means for people to give something back to the community. Volunteering has the potential to greatly increase confidence and is a fantastic opportunity to learn new skills.”
"I felt honoured when I was invited to serve as a member of the Edgar Stene Prize Jury for the second time and to represent the EULAR Health Professionals in Rheumatology (HPRs). I am always touched and deeply impressed by the very personal and inspiring essays. Being involved in voluntary work not only makes a big difference and connects people, but it also has a huge impact on health, well-being and quality of life. It is of the utmost importance that we HPRs support and empower people with rheumatic and musculoskeletal diseases (RMDs) to participate in voluntary work for as long as they want. Thanks to all the authors for sharing their experiences with the EULAR community, with other patients, physicians, HPRs and researchers. It provides us with a better understanding and inspires co-operation in the future."

ERIKA MOSOR

CHAIR OF THE EULAR HEALTH PROFESSIONALS IN RHEUMATOLOGY SCIENTIFIC SUB-COMMITTEE FROM AUSTRIA
“When I was 18 years old I was diagnosed with the rheumatic disease Morbus Still. For some years I was very sick and struggled to manage everyday life. I know how the challenges caused by rheumatic and musculoskeletal diseases can exclude some people from paid employment or a full-time role. In 2017 I was lucky to become a board member of the Norwegian League Against Rheumatism, and I am pleased and humbled to have been part of the Edgar Stene Prize Jury for the last two years. This is an important and beautiful project because the writers have invited us into their lives and their struggle. They help us readers to reflect on their lives and experiences – and maybe our own too. They are an inspiration to us all. This year’s topic is so relevant. For many of us, it is important to feel that we contribute to society and that voluntary work can offer a great opportunity. Hopefully, volunteers feel the big difference that they make, because all voluntary work matters.”