

The Edgar Stene Prize Jury 2012

Nemanja Damjanov, Rheumatologist, General Secretary of EULAR, Serbia

We are all well aware that drugs alone cannot help our patients improve their quality of life. Despite the reduction of disease activity, many patients continue to suffer from pain, fatigue, functional disability and psychological stress. Stress-evoked physiological changes, on the other hand, might have detrimental effects on disease activity. The role of rheumatologists is not only to provide medical care and treatment for their patients, but to help them cope with the physiological challenges of their condition. Stress management is important for improvements in psychological and physical functioning in patients with rheumatic and musculoskeletal diseases (RMDs). The inspiring stories written by the patients themselves can motivate others to get into grips with the challenges of their condition. These stories reveal patients' remarkable resilience to endure and to improve their quality of life. As a General Secretary of EULAR I strongly believe that our goal is not only to stimulate, promote and support scientific research, but also to closely cooperate with our patients and thus contribute towards prevention and rehabilitation. Therefore, it is an honor for me to be a member of the jury for Stene Prize this year.



Codruta Zalaban, Romanian League against Rheumatism, Romania

Being able to move around, being able to reach places means a lot for a person affected by a rheumatic or musculoskeletal disease. I live in a flat, so there are only a few steps that separate me from the world, so one might think that it is easy for me to reach out. But it is not because getting down or climbing up those stairs is not everything. Once you are in the street you don't find a well organised public street network, fitted for your special needs, you find a jungle with traps and obstacles. So, let us share the ways to tame that jungle and to master it!

**Jenny de la Torre, Rheumatology Nurse,
Spain**

Chronicity is one of the main characteristic of many rheumatic diseases. This fact, as well as the unpredictable course of the disease produces a high level of anxiety, fear and a sense of helplessness in much people with RMDs. As a nurse, I might say that we have to do a great effort for EMPOWERING patients, provide them with the tools for being more and more INDEPENDENT by increasing their self-management and self-efficacy aptitudes. I am sure, in this 2012 edition, we will have the opportunity to read many wonderful stories



**Neil Betteridge, Vice President, EULAR,
representing people with rheumatic and
musculoskeletal diseases, UK**

It is said that even the longest journey begins with a single step. For people living with RMD however, journeys are not always measured by their length, but by the pain involved, or by the number of barriers which society places in our way. It can be as big a challenge sometimes to move from the bedroom to the bathroom, as to fly half way round the world. It all depends on two things: how we feel at that particular moment; and how well our environment allows us to function. Sadly, the general population does not typically understand this. So by selecting this topic for the Stene Prize, we hope to promote greater awareness of these issues, as well as giving people with RMD the opportunity to tell their own stories of getting around. I hope you enjoy these accounts which are rich with humour, anger and frustration – but above all, with absolute determination to take that first step, which is often our very own Marathon.



**Fatima Maria Lavoll, Norsk Revmatikerforbund,
Norway**

I am married to my best friend and have 3 children. Twelve years ago I was diagnosed with SLE. For ten years now I have worked as a volunteer in the Norwegian Rheumatism Association and the last four years I was the chair of the Norwegian Lupus Group.

Many of us with a rheumatic disease have challenges in daily life to get around. But most of us are good in finding coping strategies. Some of the strategies are good but sometimes we just push ourselves too far. The topic is very relevant. It will be interesting to read this year's essays about how people overcome their challenges and are managing their daily life.



**Maria Batziou, Chairperson of the EULAR
Standing Committee of People with
Arthritis/Rheumatism in Europe (PARE),
Greece**

The Stene Prize competition is another chance for people with RMDs to express their thoughts, feelings, sorrows hopes and dreams to the public. Writing is the most effective way to communicate after love and the process of it can be healing and redemptive for the writer. When I was invited to write a few words about the 2012 Stene Prize theme "overcoming the challenges of getting around with a rheumatic or musculoskeletal disease", my first thought was that there are no appropriate words equivalent to the value of the real experiences of people with rheumatic and musculoskeletal diseases expressed through these essays. So my suggestion is to travel together through the lines, words and feelings of the 2012 essays and try to understand the messages. Then we will have managed to communicate with each other.

**Alison Kent, Rheumatology Nurse
Manager with Rheumatoid Arthritis,
UK**

This is my second year of serving on the Stene Prize jury and it has been a real honour to again be involved in this very special competition. The Stene prize is a great opportunity for those living with a rheumatic disease, across Europe to share their story and provide inspiration to others.

This year's title will raise awareness the obstacles many face on a daily basis with 'getting around with a rheumatic disease', barriers often imposed by society's attitude to long term conditions. From being able to get around in ones own community to traveling the world such challenges need to be highlighted and the way's in which they can be over come, shared. This is was this year's title has enabled, providing an insight and some answers for us all, and as **Confucius said 'It doesn't matter how slowly you go-so long as you do not stop.**

