

Edgar Stene Prize 2017

Winner: Stefanie Hulst, The Netherlands



“My name is Stefanie Hulst, I am 28 years old and live in a small town called Ouderkerk aan den IJssel in Southern Holland. I have been diagnosed with fibromyalgia. There are plenty of stories about rheumatic and musculoskeletal diseases (RMDs), and about fibromyalgia in particular, doing the rounds. Opinions differ – the extent to which it limits a person in their everyday life and what it means to live with it is a matter of debate. I consider it important that the issue is examined from experience and not so much from a purely scientific point of view because every individual is different and so is every illness.

By collecting stories of people living with this illness, we can build up a more complete picture, which says more than all the articles written by doctors across the world. They only see the issue from a medical perspective, while the person with the illness feels what it does to people.

I hope that my story can make a contribution to building up this picture and that people will be able to see that RMDs have an enormous impact on peoples’ lives. I hope that, in the future, people can look with respect at the way in which a person with an RMD keeps going despite all their pain, their limitations and, in some cases, a lack of understanding.

I heard about Edgar Stene Prize through the National Association of Rheumatism Care in the Netherlands. I see it as a fantastic initiative to put the spotlight on these strong people and their story, their strength and their perseverance.”