EDGAR STENE PRIZE 2013

GROWING UP OR GROWING OLDER — MY SECRET FOR HEALTHY AGEING WITH A RHEUMATIC OR MUSCULOSKELETAL DISEASE

eular Standing Committee of People with Arthritis/Rheumatism in Europe (PARE)
EDGAR STENE PRIZE 2013 GROWING UP OR GROWING OLDER — 
MY SECRET FOR HEALTHY AGEING WITH A RHEUMATIC OR MUSCULOSKELETAL DISEASE
The European League Against Rheumatism (EULAR) is the organisation which represents 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

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Making music with what is left

It is a pleasure and honour to compose a Foreword addressing the readers of the 2013 Stene Prize Booklet. This is the fifth Stene Prize Booklet – the first being published in 2009. It has become one of EULAR’s most valued publications today, not only within the organisation but also with policy makers at national and European levels.

This year’s topic was entitled “Growing up or growing older – my secret for healthy ageing with a rheumatic or musculoskeletal disease (RMD)”. Not only is it essential for an ageing population in general (since ageing is frequently afflicted with increasing musculoskeletal problems), and for people who have had an RMD for a long time when their age increases, it is also an extremely important topic for me as a rheumatologist. In order to ensure that people with RMDs can enjoy a good quality of life, in particular when they grow older, it is important that they are diagnosed at an early stage of the disease, and have access to rheumatologists and the most adequate treatment throughout their life – no matter where in Europe they live. Many of the essayists highlighted the successful collaboration with their healthcare teams and the important work done by patient organisations. This is encouraging for all of us at EULAR, where doctors, health professionals and patient representatives work very closely together.

Improving the quality of life of people with RMDs is the engine which drives all of EULAR’s activities. This is done by promoting better access to care, fighting for better disability legislation and, last not least, fostering research into causes, pathogenesis and new remedies. When I read in these essays that advances in treatment have enabled people who have been severely affected and disabled since childhood to suddenly experience life to the full after years of despair, it confirms what I have been – and continue to be – working for as a rheumatologist. I can use these real life illustrations when talking to policy makers at the European Commission and the European Parliament in Brussels about the necessity to allocate appropriate funding for research into RMDs and to recognise them as one of the major diseases.

Since EULAR started to become active in the Brussels European arena in 2003, the role of people with RMDs has become more visible than ever before – vital, not only in Brussels but in all our endeavours. We have been able to raise the profile of RMDs considerably over the past decade, but there is still a lot more that has to be done to ensure that the attention on – and awareness of – RMDs is kept alive and continues to increase. Today, EULAR works together with other organisations in Brussels around the topic of healthy ageing – something which receives a lot of attention from the European Commission, given the fact that the European population overall is ageing.

I would sincerely like to thank all those who participated in the competition for sharing their secrets to healthy ageing while growing up or older with an RMD. I was very touched by the determination of our essayists to live their lives to the full and to bring their dreams to reality – lives with all the difficulties and impact a rheumatic disease has to proffer, but which could not deprive them from reaching their happiness. I have learned that developing a happy and positive attitude towards life is clearly one of the secrets for healthy ageing. “Making music with what you have left” – this reference to a quote from violinist Itzhak Perlman in the Bulgarian essay captures it all.

We have the honour of presenting 10 personal stories in this year’s Stene Prize Booklet. They stand for the more than 100 million people with RMDs in Europe who live their lives with admirable courage and a positive attitude, and who are an inspiration to all of us.

Josef Smolen,
EULAR Liaison Officer
International Organisations
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”.

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 2013 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 2013, entry was open to people with an RMD aged 16 years and over. Entries can be submitted in the native language of the author and EULAR arranges to translate the 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).

“A great promoter of co-operation between doctors, patients and community workers”
The 2013 Stene Prize Jury

Each year, a panel of people with experience or knowledge about rheumatic and musculoskeletal diseases (RMDs) have the honour of judging the annual Edgar Stene Prize competition. This year we welcome our judges who represent the three pillars of EULAR and who come from a number of different countries across Europe.

In addition to the judges, the chair of the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (PARE) and the EULAR Vice President, representing PARE, help to oversee the judging and offer guidance to the overall process.

Maria Batziou has been the chair of the EULAR Standing Committee of PARE since 2012. It has been her pleasure to be involved in the Stene Prize for the second year running. Both Maria and Neil Betteridge, the EULAR Vice President, representing PARE, serve as ex-officio members of the jury and are keen supporters of the competition. Both have been impressed by the quality of the writing and the enthusiasm from all entrants.

“I always believe that, when people are able to share their emotions, concerns and thoughts with other people, they are able to cope with the difficulties in their life in a more effective way. Writing is one of these tools that can have a healing effect,” says Maria of the Edgar Stene Prize 2013. “I am very happy that the Stene competition gives this opportunity to people and I have enjoyed the journey through the emotions and thoughts of those people who have been brave to share their experiences with all of us. They remind us that living and growing older with a chronic disease doesn’t necessarily imply just difficulties and pain but also strength, endurance, hope and caring about other people.

Let’s read the stories together and share the experiences of those who were chosen by the judges. These people live their lives with a chronic disease and have learnt how to make it a positive journey. Is this the definition of what we call quality of life?”

Neil is equally as enthusiastic – especially as this year’s theme has particular meaning to him. “It has been both an honour and a pleasure as Vice President of EULAR, representing PARE, to serve as an ex officio member of the Stene Prize Jury,” says Neil. “This is my final year in the role and this is one of the functions I shall miss the most. Being part of the team involved in reading the essays every year has been a privilege of the highest order because of the way people with RMDs so generously share their experience, insight and personalities. It is truly inspiring.

This year I feel an extra special connection with the topic. I was three-years-old when I developed juvenile arthritis, so reading the stories of people who have grown up, as well as older people, with an RMD has been truly empowering. They say the only constant is change and, as we grow and develop throughout our lives, change is challenging for everyone. But it can be extra challenging for people living with the impact of an RMD.”

The 2013 topic relates back to EULAR’s new focus on RMDs and Healthy Ageing under the World Arthritis Day theme of “Living better, ageing well”. The jury members were excited to invite people with RMDs to write about what they do in their daily lives to age healthily with an RMD – be it a diet, exercise, relaxation programme, meditation, fun, the family or any other secret! With 19 organisations submitting essays to the 2013 competition, the response was one of the highest numbers ever received – clearly demonstrating that there is a great deal of interest in this topic and a lot to share.

Entries were sent to the EULAR secretariat by EULAR member organisations from Austria, Belgium Wallonia, Bulgaria, Cyprus, Czech Republic, Denmark, Germany, the Former Yugoslavian Republic of Macedonia (FYROM), Greece, Hungary, Ireland, Norway, Poland, Portugal, Romania, Serbia, Sweden, Switzerland and the United Kingdom. Several organisations participated in the competition for the first time, while others reported that it had been the most successful national competition ever – the Swedish organisation received more than 30 essays.

Once again it was very difficult for the jury to choose the winner. All the entries were of a high standard and each one of them presented a unique angle on the overarching topic. In order to compare the essays, the jury members were asked to give ratings for creativity, writing skills and the inspirational aspect of the stories.

Jolanta Grygielska, PARE Board member from Poland, is Leader of the 2013 Edgar Stene Prize Jury.

“It has been a pleasure and honor for me to be involved in the Stene Prize jury. I was a member of Polish national jury on this project due to my many years working in...
are represented by The EULAR health professionals responsible for their future."

of their situation and to be more opportunity to remain more aware will give people of every age an very interesting. I hope that this connected with healthy aging, is them. This year’s theme, lives and I learned from many of emotions and experiences. I felt like an unnamed witness of their studies and I learned from many of them. This year’s theme, connected with healthy aging, is very interesting. I hope that this will give people of every age an opportunity to remain more aware of their situation and to be more responsible for their future.

The EULAR health professionals are represented by Jana Korandova from the Czech Republic. She is chief nurse of the Prague Institute of Rheumatology and chair of the Czech Health Professionals in Rheumatology.

“This year’s topic is so current, so cool and so inspiring! When writing their story about ageing with an RMD, none of the authors will have done so without switching on an imaginary screen – like a life film show. I am sure the screen would have been multicoloured, but would also have been full of surprises and of new knowledge about themselves. ‘What was it that you had to leave because of your disease but, also what good happened due to your problems?’ ‘What, or better, who, were the most important people who helped you to get through and why they did so?’"

Writing your story has shown us how strong and how unique you are! It will have shown you the amount of amazing people – who are always ready to help – who are surrounding you! Thank you very much for sharing your film of memories with us.”

Gerd Jenny Aanerud from Oslo has lived with rheumatoid arthritis (RA) since she was in her 20s. “Being 53 years old and having lived with RA for nearly 30 years, I think puts me right in the group of people growing older and living with RMDs. My secret is to be active, still work part-time and exercise on a regular basis.

I have always admired Edgar Stene for his work. His thoughts regarding a companionship between patients and health professionals has kept me busy for many years.

I found the job of being a jury member very intense and very interesting. I read each of the essays several times, giving myself a day or two in between. Every time I made comments and, at the end, I gave each essay a score. After that, I compared my various comments and found that, generally, I agreed with myself – but I found myself somewhat surprised a few times also.

I shared the essays by reading them out loud to my husband and by letting my daughter read them too. We had some nice discussions.

I had three favourites, but I believe the older lady with the white hair was the first to touch my heart. The story of the wolf and the butterfly was intriguing and written like a short story or novel.

I learned that the painter Renoir had rheumatoid arthritis. I did not know that, but now I have read up about him too.

So thanks again for the opportunity to be a member of the jury.”

Lena Andersen, 51 years old, was diagnosed with rheumatoid arthritis in 1994. Although she has taken early retirement, she is very involved with the community and enjoys many hobbies.

“Being part of the Stene Prize jury has given me the opportunity to learn more about how other people handle their daily lives with an RMD.

The competition’s topic is very relevant as there is a lot of focus on healthy lifestyle in society – and healthy ageing is connected to healthy lifestyle. I believe that I live quite a healthy life myself – with all the exercise, vegetables and fruits, olive oil, full grain products and so on. But maybe that is not the only answer to healthy ageing? People’s stories inspired me in my ‘further search’ for healthy ageing.

To me, the Edgar Stene Prize competition is of great importance because this is where patients have the possibility to tell their stories, share their experiences and to be heard. My wish is that as many doctors and other health care professionals as possible will take time to read all the essays.”

Nemanja Damjanov is a rheumatologist from Serbia. He is also Secretary General of EULAR. “Growing up and/or living healthily with a rheumatic disease is a huge challenge and an agony for many people. However, this year’s Stene Prize competition introduced to us to several amazingly optimistic, courageous and persistent people and their life stories.

As a rheumatologist, I am fully aware of all possible obstacles and problems my patients face and have to deal with on daily bases. This is why I sincerely admire their perseverance and stamina in struggling with their condition. What astonished me most is their remarkable optimism, sense of humour and wittiness, despite the harsh reality of living with some of the most severe diseases. The authors of the essays set excellent examples of how to keep a positive perspective, make the most of your life and never give up your dreams.

It’s been an honour and a pleasure to be a member of the jury for the Stene’s Prize once again, and learn about some exceptional people who never give up the fight.”
How did you react when you heard your contribution had won the 2013 competition?

**Mette:** I was absolutely thrilled – as well as honoured! I was also really excited about the opportunity to participate in the EULAR Congress in Madrid.

These huge annual gatherings are magnificent and unique I think – where experts on various rheumatic diseases from all over the world and patients are welcomed on an equal footing.

The Stone Prize is a very special prize, reflecting the importance assigned by EULAR to the patients’ perspective. So I am really happy and proud to have won the prize this year.

**You have a very positive attitude and enormous strength to deal with difficulties. Where does this strength come from?**

**Mette:** That is a very hard question. The easy answer would be that it is probably due to some specific combination of genetic and environmental factors. Well, if there is a gene for positive attitude and mental strength, I probably have it.

The workings of environmental factors, however, are much more difficult to sort out, if you ask me.

I think of myself as having had a happy childhood. And I really did, in many respects. But I could also tell an equally true story filled with childhood memories that most people would call sad or shocking. As a child – and well into adulthood – I made a point of not telling anyone about the “traumatic” stuff, because I didn’t want people to think of me as being different or damaged because of that. Today I don’t mind telling people about these things, but why bother. Bad stuff happens, but it doesn’t define who you are.

Diseases or diagnoses do not define who you are, either. You are still you. And, as the song goes: “What doesn’t kill you makes you stronger”. Right?

As many fellow patients will attest, if you can steer clear of self pity, having a serious disease can make you a more focused, a more appreciative and a more positive human being.

**What would you recommend for people with RMDs who are having a difficult day, when pain and frustration can easily take over?**

**Mette:** If it is just one difficult day, don’t fret; just take it slow. Listen to what your body tells you. Maybe it tells you to call in sick or to rest more than usual. Or maybe it tells you to go for a walk or to do your fitness routine.

Distract yourself from the pain with your favourite entertainment or some creative activity. Allow yourself to feel frustrated, if you absolutely must, but not for more than two minutes.

Frustration will get you nowhere. The answer to frustration is acceptance and action. If you feel worse than usual and for more days in a row, you should definitely call your doctor and get an appointment.

**What can patient organisations, like Gigtforeningen, provide to support people with RMDs in different phases of their life?**

**Mette:** Patient organisations can provide information, general advice and personal telephone counselling on all the different aspects of living with RMDs. They can support networks where patients can meet other patients with the same diagnosis, with special networks for younger patients, and so on. Gigtforeningen does all that.

A recent initiative is a patient education programme, “Know Your Lupus”, which has been a great success.

**Healthy Ageing is also a hot topic for policy makers – what would be your call to action for policy makers so that people with RMDs can grow up or grow older as healthily as possible?**

**Mette:** Basically, whether a person has a disease or not, choosing a healthy lifestyle is the responsibility of the individual, I think. My essay is about that.

Policy makers should make sure that people with RMDs get an early diagnosis and the right treatment without having to fight for it. That is really important for a good outcome.

In order to reduce the number of people getting sick in the first place, policy makers should also take action to improve the environment. Undoubtedly our modern lifestyle, with loads of unnecessary chemicals everywhere, plays a part in many diseases, including the autoimmune ones.

**What are your dreams and plans for the future as you grow older?**

**Mette:** That’s easy! My plan is:

- To continue to work full-time as a professor of Japanese at Copenhagen University.
- To grow older?
- To grow up or grow older as healthily as possible?
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Growing up or growing older – my secret for staying healthy with rheumatism

When the World Health Organization (WHO) was established in 1948 under the auspices of the United Nations, it was, of course, necessary to define what health actually meant in its constitution. They came up with the following grand statement: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.

This definition has since been criticised, not least for being unrealistic, and for defining happiness rather than health. But I find that, for those of us who have been diagnosed with an illness, it is particularly problematic and annoying that, according to the WHO, we cannot – by definition – be healthy because we are sick.

The topic for this year’s Edgar Stern competition clearly takes a different definition of health as its starting point – one where health and illness are not opposites, but where health is something we can strive for whether we are sick or well. Hurrah! I quite agree. Of course it is possible to be healthy even if you are ill, just as someone can be unhealthy even if, on paper, they are well. So here are a few of my tips for how to make the journey from cradle to grave in reasonably fine fettle in spite of chronic rheumatic disease.

“Health and illness are not opposites”

Health secret number 1: Don’t worry – be happy!

“Tell me, how can you sit there smiling when you have all those illnesses to contend with?” a neighbour asked me recently when we were having coffee together. She meant no offence; she was genuinely mystified. I was totally stumped. How could I answer her? “Sorry, it was wrong of me. I won’t do it again!” or “Well, you know, it’s just a brave face I put on when I’m in good company!” No. After a brief pause for thought I could only tell her the truth: “But that’s just the way I am!”

“That’s just the way I am”

Once again, I was reminded how lucky I am, because I am, at heart, a happy soul. However, I also think that a positive outlook on life is something you can consciously choose and try to hold on to – and that it pays to do so because it makes life so much easier, whether we are sick or well.

That cheerful disposition stood me in very good stead when, in the autumn of 2005, I came down with what I thought was a bout of flu. From then on the diagnoses began to rain down on me. I was 48 when, all of a sudden, I went from being fit and healthy to sick and wretched.

Systemic lupus erythematosus was the first interesting diagnosis I had to get acquainted with, and a handful of additional diagnoses followed in swift succession: Sjögren’s syndrome, Hughes syndrome, steroid-induced osteoporosis and discoid lupus, among others.

At that time, when I was at my most ill and exhausted, and unable to do much else, I hit upon the idea of putting myself through a kind of laughter therapy. It didn’t come naturally to me to laugh out loud at any old thing the way some people can. Instead, I sought out funny books, films and TV series, absolutely determined to laugh long and loud if anything was even the remotest bit amusing. I laughed like a madwoman – and had to reassure my husband, who was initially alarmed, that it was deliberate.

Does it work? Yes. Try it yourself and see! It is very hard to brood on things and remain tense when you are laughing out loud, isn’t it? But it doesn’t even take as much as that. Try just a big smile. Don’t you feel much better already?

Health secret number 2: Health recommendations only help if you follow them

I wonder if I am the only person who is tired of listening to all the talk about health and slimming. Tired of TV programmes about people who need to lose weight, instead of proper entertainment that makes us laugh. Tired of the glossy pictures in women’s magazines of beautiful, well-turned-out people eating correctly and exercising properly in smart outfits, showing us how it should be done.

Honestly, this is just too feeble and excessive. Grown adults who need a personal coach in order to eat sensibly, and other grown adults who devote a large number of their waking hours to keeping fit and looking good? Don’t we have more important things to achieve here on earth in the short time we are here?

Enough of this! We have heard all the recommendations, ad nauseam. Whether we take them on board is up to us. Whether you are sick or well, you are sure to be able to find plenty of excuses for your hard luck. But one thing is certain: health recommendations only help if you follow them, and no one can do that for you. Not your mother, not your doctor, not your Aunt Nelle.

If you want to stop smoking, just make up your mind and do it.

If you want to eat a healthier diet, only buy and eat healthy food.

If you want to lose weight, just eat less and check your weight morning and evening.

If you want to put on weight, just eat more and check your weight morning and evening.

If you want to exercise more, just get up off the sofa, turn off the television, log off from Facebook, and get going!

Enjoy your healthier lifestyle instead of feeling sorry for yourself – and then use the new energy this gives you to do some of the things you want to do. And above all: do something that makes you happy!
My name is Bozhidar. I am a 56-year-old sociologist living in Sofia. I am divorced with two children – a daughter and a son – and I have two wonderful grandchildren.

I work as associate professor in the Institute for the Study of Societies and Knowledge at the Bulgarian Academy of Sciences. My professional interests and fields of research include the sociology of disability, social policy and social work with disabled people.

In my spare time I work as a volunteer for the Bulgarian Organisation for Patients with Rheumatic Diseases (OPRZB) and the Bulgarian Ankylosing Spondylitis Patient Society. I try to help them with my expertise on various social aspects of rheumatic diseases: legal advice, aids, etc and also as editor of their newsletters. I am also the editor of a scientific and popular science magazine called Bechterew’s Searches.

I found out about the Stene Prize competition from OPRZB’s website and Facebook group. I decided to take part and share my own, perhaps rather unconventional, experience of coping with Bechterew’s disease, which I have lived with since 1971.

When I read the competition topic I remembered the words of Montaigne, who described old age as a powerful disease that develops naturally and unnoticed. “My God,” I said. “How can you talk of healthy ageing with Bechterew’s disease, where the pain feeds on your flesh and doesn’t stop trying to consume your spirit?”

“I had failed to see the deep psychological and social aspects of the topic”

But when I first read the topic I hadn’t quite realised that I was seeing it only within its biological context, where it loses all meaning. The terms “healthy”, “ageing” and “rheumatic disease” taken together, mutually exclude one another. They are separated and lose their meaning because of the supremacy and dominance of suffering and pain, which narrow your world only into them. They shrink your world to dependence, to the imposed role of patient, to total medicalisation, to… I had failed to see the deep psychological and social aspects of the topic, the dimensions of which were much more important and truly meaningful.

I first saw the light when I read a short story about the musician Itzhak Perlman. At one of his concerts, this genius, who suffers from polio, painfully made his way on to the stage, finally sat down, put down his crutches, unbuckled the harness supporting his weakened arms, picked up his violin and started to play. He took his audience into the realm of light. But after the first few bars, fate intervened and one string of his violin snapped. Nobody thought he could possibly play a symphony with a string missing. But Perlman did. He continued to play, changing the music, composing and adapting it to his “crippled” violin.

“The audience realised that they had witnessed a miracle”

And afterwards? The audience realised that they had witnessed a miracle. The musician’s superhuman efforts had helped them overcome something inside themselves. Perlman smiled and said modestly: “You know, sometimes the point of music is to make music with what you have left.”

Making music with what you have left… Being a person despite the disease, the pain and the suffering, and to find in yourself the strength to reach out to the people next to you and help them to win life’s little victories.

“… Being a person despite the disease, the pain and the suffering”
This brought to mind another story I’d heard. At the Seattle Goodwill Games, there were nine athletes on the starting blocks for the 100 metres sprint. They were all young people with various physical and mental disabilities. The starting gun fired and they were off. However, about 30 metres in, one boy tripped, stumbled a few paces and fell. He started to cry. The other athletes heard his cries, looked at each other and stopped running. One girl with Down’s syndrome joined the fallen boy, gave him a hug and said: “Do you feel better now?” After that, all nine of them crossed the finishing line, shoulder to shoulder together. The whole stadium broke out in applause.

I realised that, throughout my life of fighting the pain and the slow but relentless onset of functional deficiencies that Bechterew’s disease brings with it, I had never been able to run or play an instrument. Words were the only thing I had. And all the time, whenever the pain tripped me and I would fall, or a string snapped in my soul, there was always a friendly hand extended out to me – my unquenchable thirst for knowledge. The hand of knowledge. There was the word. Aristotle, Montaigne, Pascal, Nietzsche, Weber, Durkheim or Hadjiski. Balzac, Dostoyevsky, Dickens, Vazov and thousands of other enlightened minds were there beside me, offering me a hug or a new violin. And I kept on getting back up and carrying on – I carried on playing the small and chaotic symphony of my life.

“I carried on playing the small and chaotic symphony of my life”

After years of opposing medicine’s attempts to break me down into organs, systems and what have you, I paused and started trying to help those around me – the “others”, those who were “different”, to get up and carry on playing, to play first fiddle in their own lives. That I was lagging behind didn’t matter.

All I have are words. Words, which Sartre once described as loaded pistols. I melt them down and create small, silly and unpolished images of hope, of resistance – little figurines of knowledge – and attempt to share these with my friends. That is how I age well with Bechterew’s disease. The rest – medicine, pain, trying to deal with pain and suffering – seem to have been relegated to second place.

Ageing well with a rheumatic disease is a state of the mind, not of the body. There is nothing beautiful or dignified about age, disease and death. The beauty and dignity lie in the choices we make. And I cannot – and will not – allow the disease or time to win the fight and make me invisible.

“The beauty and dignity lie in the choices we make”

Editor’s explanations:
Bechterew’s disease is a name sometimes used for ankylosing spondylitis
Lenka Krejčíková

My name is Lenka and I’m 51-years-old from Železná Ruda. I have systemic lupus erythematosus and live on a disability pension. I enjoyed a healthy childhood and was successful at all kind of sports – I played tennis, table tennis, and loved running and gymnastics. My problems started when I was 17. I fell into a coma, had a fever, and developed heart, muscle and joint problems. But my will and the careful treatment I received helped me to overcome this most difficult period and I even graduated successfully from high school. I married and gave birth to four healthy and wonderful children, and I am already a proud grandmother of five!

I heard about the Edgar Stene Prize from the Lupusinky profile on Facebook. I decided to write an essay because I already enjoyed reciting and writing at school, and participated in several competitions. I wanted others to know how people with systemic lupus erythematosus feel. My desire to live can overcome many health problems but I have to carefully choose my activities as my energy is limited.

I just need to tie up my shoelaces and then I can get going. I decided it would be best to forget the jacket. I want to feel comfortable and I don’t like to be too hot. I’m quite looking forward to this. My plan is to run at least five miles. Maybe more.

I like a bit of exercise. It clears out your head and makes you feel pleasantly tired. On this occasion, my years at secondary school come flooding back to me. Even then, I used to compete in running and air rifle shooting. Truth be told, I wasn’t much good at distance throwing or the shot put. But I did love tiring myself out with cross-country running. It was much easier to concentrate on my schoolwork after a good run.

As I approach the forest, I meet a neighbour walking his dog. I stop for a moment to caress the animal. I love all dogs. They are far better than humans. They won’t let you down and they don’t sulk. Leaping over the stream, I push on quickly, mile after mile. But now I start to run out of strength. I come to a halt in the middle of a meadow, take a few deep breaths and sink down onto the soft, velvety grass. A feeling of lethargy overpowers me and I stretch out gladly, with a sense of relief. I trace the glowing lava of the sun overhead and listen to the rustling branches of the trees in the nearby forest. It feels wonderful.

I switch off all thinking and let the waves of happiness wash over me.

But what can that be? There’s a sharp pain in my leg. And another… Another… Enough!

I leap up and see, to my horror, that there is a wolf attacking me. Where did he come from? He bites and bites again. I’m confused… The wounds are agony. I must get away from here as fast as I can and find somewhere safe. I try to run, but nothing happens. I silently block out the pain and move one leg.

Opening my eyes, I am confronted with the white ceiling of my high-rise flat. Under the duvet, my legs can hardly be cajoled into any movement at all. I take off the duvet to see how many wounds have reopened. Not too many. I perform a few leg exercises so that I can get up. I say exercises, but those movements are anything but. Nevertheless, I’m grateful even for so little.

“My legs can hardly be cajoled into any movement at all”

I slowly shuffle out of bed and shake my arms and legs. I am standing – I have won. Another day of happiness. I am on my own two feet… I smile.

What do I fancy for breakfast? I think I’ll have some fruit curd. It tastes great and, what’s more, it’s healthy too. But let’s freshen up first! The cold water streams down my cheeks, there where the beautiful butterfly perched. He has often done it, pausing on his silky way to rest there, displayed in all his glory. The first time he tried to do this, it scared me half to death. But we’re buddies now, and he often flies in to visit me and lift my spirits. I accept him as another friend. I imagine how fine I must look with him sitting there. After all, a butterfly is a beautiful thing.

I pile mandarins, bananas and curd willy-nilly into a dish and then think about what I am going to do after breakfast. My tummy feels nicely fed. Medicines next, and I’m all set! I prepare several brushes to be on the safe side. I have to
choose the right ones for the size of the canvas. I opt for smaller ones. Now where did I put those new oil paints? Here they are. Oh heck! That really annoys me. My fingers are refusing to cooperate again. However, I know a few tricks that will help a little.

There! All ready! Have you worked it out yet? Yes. I have decided to paint my good friend the butterfly as he appears in my mind. Only I’m not sure if I can capture the right purple that coats the thoughts in my head. Steady now… Steady… I must concentrate on holding the brush firmly. If I drop it, I’ll ruin the picture.

“Any minute unused is a minute wasted”

A beautiful butterfly takes form on the canvas. Its fragile, silky wings sweep through my soul and wash my imagination in a layer of many-shaded purple, intermingled with a snowy white.

I place the picture slowly and gently on the living room chest. I just need to clean my brushes and I’ll be done. Extreme weariness then descends. I sit down in an armchair and reflect on immortality and the may-bug.

But soon these thoughts depart. Any minute unused is a minute wasted. So I pick up my English textbook for beginners and self-learners, and start revising the words and phrases I have learnt. Progress is slow, but it’s progress all the same. What I wouldn’t give for a better memory! I’m still young, but part of my memory belongs to the butterfly and to that wolf who chomped down on my legs so hard I can’t pull him away.

Well, I’m a little bit wiser, I tell myself after studying for an hour or so. I abandon the chair to seek the support of a good lunch. Through the window, the sun tips me a wink and the turquoise clouds chuckle. I pick up my crutch, slip a sweatshirt over my t-shirt (to fend off the cold) and step out into the street. I remember a beautiful dream in which I ran on for miles, leaping over streams and brooks. I pause for a moment, lost in thought.

Slowly, but surely, sadness takes hold. As luck would have it, a small dog stirs me from my reverie, begging to be caressed. Clumsily, unevenly but resolutely I set off on what will at least be a short walk around the block. On the way, I meet a man in a wheelchair and realise that I should be thankful for what I have. I smile at the man and he smiles back at me.

With peace of mind restored, I wobble home and settle back contentedly into my chair. Eyes closed, I recall the man in the wheelchair. Despite his infirmity, he is happy in this world. I admire him. I realise that fate could have played far worse games with me. And that, thanks to lupus, I have two new friends – a wolf and a butterfly. I have indeed been fortunate.

“I realise that fate could have played far worse games with me”

With my son - writing at the computer

Editor’s explanations:
“willy-nilly” means disorganised or haphazard
“Oh heck” is a term used to express surprise or frustration
Annette Siegert, Germany

My name is Annette Siegert and I live in Berlin. I love the city but also appreciate nature.

I was diagnosed with systemic lupus erythematosus in 1999 when I was 25-years-old. I am now 39 and have been drawing a pension since 2008.

I would love to have worked as a town and country planner or event manager but, due to the severity of my lupus, these dreams could not be realised. But I enjoy being a hobby beekeeper and just recently decided to join a cross-cultural garden project. I will be looking after my own garden bed soon – very exciting! I sing in a choir, learn Russian and live life as best as possible given my health limitations and financial restraints, which sometime challenge my creativity.

The Edgar Stene Prize is a wonderful opportunity to gain a greater understanding of the everyday life of patients with rheumatic illnesses.

I was 25 when I received my diagnosis. A woman lay in the bed next to me whose body was totally wrecked – her eyes, kidneys, lungs, hair and skin devoured by the wolf. She was about 50-years-old but she looked like an old crone. Everyone who saw her turned away from her, full of horror.

Lupus had wreaked its havoc in her 20 years previously. This is what I learnt on the ward round, though I didn’t speak a word with her myself.

I calculated: 25 + 20 = 45. Because I was always an optimist I added five years to it. So I would die a wretched death at the age of 50 because of my lupus.

Thirteen years and four episodes later – years which were a seemingly endless repeated sequence of hope and despair, again and again – suddenly something rather like a future suddenly cropped up. Something about which I no longer knew. Something I no longer believed in or hoped for. Something I was afraid of. I was afraid even to think about it!

For me, future meant the period till my next treatment, till the next laboratory test. Future was two weeks, three months, till the next holiday I planned alone because the risk was too great that I would have to cancel it after all because I felt poorly again.

A year away – that was an unattainable distance, an elusive goal that I would perhaps never achieve and if I did, in what condition?

“Without a future, life shrinks and contracts”

Without a future, life shrinks and contracts. Everybody makes plans – children, houses, careers, holidays. For a long time, I just planned the next day or week. Just to live in the here and now is a desirable way to be, and everyone who is always just planning and rushing years for it.

“What if you have no choice at all”

But what if you have no choice at all – if there is a wall behind the here and now that you can’t get beyond and you can’t see any future? The result is that you derive endless enjoyment from the time that you are indescribably happy for brief moments.

But it also makes you lonely, separated from other people. How can you forge plans with healthy friends, plan a future with a job, get into a relationship or start a family, if you are ill? How can you stand on your own two feet in a healthy world and grow...
old and adult in it? If you feel helpless and ill – like a small child, dependent on the help of other people, no longer able to take care of yourself?

It is difficult to find a place somewhere in the middle between illness and a normal life. And yet it is very important for me to have this place where I can be with all my weaknesses but also with my strengths, which are still there despite the illness. To be there, adult, independent and confident, but being able to accept help when it is necessary.

“I no longer need to hide away in my state of illness for fear”

I find it easier and easier to manage the older I get. I no longer need to hide away in my state of illness for fear of not being able to keep up. I want to be part of things as often as possible, but also enjoy my breaks and peace.

“I would like to make lupus a normal part of my life”

I would like to grow older with other people and not stay alone in my illness. I would like to make lupus a normal part of my life and not let it separate me from my fellow human beings. In order to feel good and keep active, I do yoga and go swimming regularly. It keeps my body soft and strong at the same time. I sing in a choir and laugh a great deal with friends. I am learning Russian and planning trips. Perhaps I will even dare to fall in love again, have a relationship without being afraid that my illness could be too great a burden.

“My future is getting broader and bigger”

For a year, I’ve been responsible for a colony of bees – it’s something that needs me. And it teaches me to live with the seasons, in a completely unhurried way. Quite slowly, my future is getting broader and bigger again, sometimes I dare to dream about it and allow myself to long for something else.

I am still afraid of dying a wretched death because of lupus. And even when I die, I don’t want to be alone. I have made an agreement with a friend. Each time he flies, he is afraid of crashing; and I think, each time I fly, how nice it would be to crash after a wonderful journey instead of vegetating away in hospital. In 40 years’ time, we will search out the oldest and most rickety plane that we can find – and fly it.

By then I will be 78 – 28 years older than I once calculated as I lay full of fear in a hospital bed. I’m still optimistic, even after 13 years with lupus.

“Quite slowly, my future is getting broader and bigger again, sometimes I dare to dream about it and allow myself to long for something else”
Letting a stranger into my life

Theodora Seitanidou, Greece

My name is Dora and, in December, my birthday cake will be decorated with 32 wonderful candles. Juvenile rheumatoid arthritis (JRA) came to me when I was six years old and, since 1998, my hips and knees have been replaced by titanium in several surgeries.

I am single but I have a lot of kids because I studied as a kindergarten teacher. I've been very lucky because I have lived and worked on different Greek islands for three years, gained unforgettable memories and made strong friendships which will last for a lifetime.

I decided to participate in the competition as I consider writing to be one of the arts – and I strongly believe that art calms and reveals our soul! This is a reason I have an intense hope of becoming an art therapist to try to help myself and others!

If someone would ask me to share my treasure box with them, in it they would find my family, my friends, journeys and efforts to have fun under any circumstances!

Generally, I strongly believe that the word “acceptance” is a magical one... A word that leads to a path of self-composedness. Personally, I do not embrace the significance of acceptance in all aspects of my life! I do not have the strength. I consider that the time I “give in” to acceptance will be the time I will lose... Lose what? I haven’t the slightest clue! The battle I fight on a daily basis? Myself? The JRA? Stupid, insensible thing! As if I could win.

Perhaps, it is something to keep me alert... To never stop struggling – to fight, to live

Twenty six years ago, a stranger knocked my door and I just opened it. He liked me very much and, since he was homeless, he instantly took the decision to stay with me. To be accurate, he became my permanent room mate. This cohabitation brought all sorts of difficulties with it, especially when it was absolutely not my choice!

And his name was juvenile rheumatoid arthritis...

The truth was that I didn’t get to know him very well at first, but living with him made me learn. I learned that he loves surprise parties: you go to sleep with sweet dreams and you wake up truly exhausted after the celebration he has set up with your hormones!

“A stranger knocked my door and I just opened it”

I learned that he very much likes to pay visits and he is very selective as well – he adores mostly hospitals. He enjoys hospitals so much that a lot of times he decides to sleep in their comfortable beds.

“I living with him made me learn”

I learned that he is fond of journeys – he travels a lot to the knees, the elbows, the neck, the hips... And, in some places, he buys houses too.

I learned that he goes for various flavours – not the ones to everybody’s taste but those which are a bit hard to find. You can only purchase them in
selected stores – “drug stores” I see is their name!

I learned that he is very sociable – he doesn’t prefer loneliness so much and occasionally chooses to hang out with other diseases. You see, they have so many things in common.

“He is not a close friend and has a bad attitude”

I learned that he is not a close friend and has a bad attitude. He steams up when he is not cheerful and bursts into my body! He can be very mean – he makes me hurt just to wake me up and make him happy again!

I learned, especially in recent years, that he is a healthy-way-of-life maniac! Exercise, proper nutrition, positive thinking… He is like a guru.

“He is a healthy-way-of-life maniac”

I learned that he is obliged to spoil himself. He is capable of using a taxi for a 10-minute distance so as not to be tired and to have enough strength to dance himself out!

I learned that he likes to collect gadgets – special devices and products that make his life easier. He is, for certain, a bon viveur.

I learned that he now has the knowledge and the wisdom to recognise that any interference with his existence will assist him to improve his quality of life and thus to get him closer to happiness.

I learned, after so many years, that the best way to live with him is to concede all his imperfections. After all, a wise Greek proverb says “accept your friends with their flaws” and JRA has eventually become my best friend.

“After all, a wise Greek proverb says ‘accept your friends with their flaws’ and JRA has eventually become my best friend”

And last but not least, don’t you ever forget that ACCEPTANCE is just:

- A
- Cloudless
- Cocktail
- Evening
- Party
- Trying
- Avoiding
- Not
- Caring
- Evolution.

May you all make your life a peaceful and interesting place to live and explore.
Growing up with a positive attitude

What can I tell you about myself? My name is Siobhan O’Shaughnessy. I’m a teenager. I’m into make up, music, concerts and my boyfriend. Oh yes and I have juvenile arthritis. I’m 17-years-old, but by the time you will have read my essay I will have celebrated my 18th birthday. What a milestone! To many people, I’m probably “a little girl” but, to a young lady coming of age, it’s like opening up a whole new world.

Looking back over my teenage years, it has been a challenge. At the tender age of 15 I was diagnosed with juvenile arthritis. It took a long time to get to that diagnosis and, after many bouts of sickness, flares, painful joints intertwined with my parents and brothers almost going insane with worry, it was almost a relief to hear the consultant saying: “You have systemic juvenile arthritis”.

With my mother trawling the internet to get every bit of information she could put her hands on to understand my diagnosis, and bombarding my consultant with questions and taking photographs of flares and swollen joints, it wasn’t long before we knew what we were dealing with.

I have just moved into the adult rheumatology department from paediatrics and, to this day, I think the best thing that happened to me was meeting my rheumatologist consultant at Cork University Hospital. He took charge of my illness in a vigorous and adamant manner. A young man, friendly, talkative and, most of all, I had found someone who was interested in listening to me. He always welcomed my parents as well as me to every appointment and, no matter what decision his team made, he was always the one to make the final call on my care. I trust him to make wise, smart and informed decisions based on my needs and what is best for me.

“I had found someone who was interested in listening to me”

During a social networking event on Twitter, my mum learnt that there was a very active organisation in Ireland which dedicated itself to people with rheumatic and musculoskeletal diseases (RMDs.) After initial contact and a lot of support given to our family by Arthritis Ireland, I look back now over the past two years and think “where would I be without them?”.

That was the beginning of my journey with living openly and accepting life with juvenile arthritis. They have supported and encouraged me beyond their duty. From a quiet, shy, introverted teenager to a happy-go-lucky young lady, I have recently been an advocate for “juvenile arthritis”. This involves encouraging other teenagers and young people to come forward and talk about their challenges of growing up and living with arthritis.

I did this by writing an article to raise awareness of arthritis in young people in our local newspaper. I also went on national radio, 2FM, speaking to the nation about my story so far, and how I deal with living with arthritis on a daily basis.

The day I spoke on the radio, it was from my hospital bed: I had been admitted with a bad flare up. But being in hospital was not going to keep me down and I certainly was not out! This was
the perfect time to tell people what it was like to miss school and have friends forget about you when you’re “out of sight, out of mind”. More importantly, I told anybody that would listen to encourage others with arthritis to get active and involved in their local community arthritis network.

I told the radio audience that my family had been asked to be arthritis ambassadors in the summer of 2012, so anybody at all who knew me had “waved for World Arthritis Day”.

A photographer from the local newspaper took many shots of me walking along the beach on a bright sunny morning in beautiful surroundings. This photograph would accompany the headline “Siobhan is just 17, recently abseiled down a cliff but suffers from juvenile arthritis”. That headline was the first time my story was being told to the public and it felt so liberating! Even family members were very taken with my story and it opened up a lot of conversation around support and illness in young people. The school principal proudly displayed the article in the school for everyone to read. At last my friends and teachers could read it for themselves – I didn’t have to explain why I was able to be in school one day and maybe missing the next!

So that was the beginning of me wanting to raise awareness and support other young people with arthritis. I believe I have a lot to offer. I like to encourage all the young people I have met through Arthritis Ireland to be a support network for each other, to lean on each other and talk through any concerns we may have together, and learn from each other’s experiences.

We all attended a youth workshop that was organised by a young woman from Arthritis Ireland. I went on that trip on a Friday with a lot of anxiety and “what ifs” as I did not know too many people going. By the time I had left on Sunday evening I had participated in youth workshops, learnt coping mechanisms for dealing with pain and, last but not least, had abseiled down a cliff. Me, yes, me! Abseiled down a cliff! When I went there, I had an aversion to the “Great Outdoors” and here I was coming home with a certificate for abseiling. My arthritis was not going to hold me back!

The people I met on that weekend are now some of my closest friends and I couldn’t imagine them not being in my life.

“...the people I met on that weekend are now some of my closest friends”

So in October my abseiling picture appeared in the arthritis newsletter and my consultant arrived at my bedside with a copy in his hand, congratulating me on my achievements and for raising awareness for juvenile arthritis. This gave him and me more determination to get my arthritis under control and to accept it gracefully. I promised to keep challenging myself through different activities, promoting awareness of arthritis in young people and getting people to realise that arthritis is not just an “old person’s” disease.

There you go! From a very low activity, Facebook, Twitter, social networking junkie sitting on the couch, I am converted to challenging myself by trying out new activities. Abseiling is not a practical everyday activity, but I do realise that swimming a few lengths a couple of times a week or just walking to the shop for that bar of chocolate instead of getting a lift in the car has more benefits than a little sugar rush. That’s my excuse and I’m sticking to it!

I have adjusted my mind to try not to limit myself and to accept challenges that come my way. I believe that a healthy mind will help me have a healthier body. I will always push myself, but within my own limitations. I know when I should stop or when I can give that extra little bit of effort. It might be a day that I can just make it into school for a couple of hours but at least at the end of the day I can look back and say “yes I have achieved something today”!

What is so ordinary to other young people who do not suffer from an RMD is a daily challenge for us, and achieving something small can be a big reward for RMD sufferers!

“Achieving something small can be a big reward”

So that’s me in a nutshell. From back then at age 15, not being able to get out of bed to now being on biologic injections and accepting and respecting my illness medically. I believe that my wellness is much wider than taking medication. Whilst it is a crucial and important part of my care, I believe that opening my mind, my heart, and trusting and respecting people is the key to helping others to understand me, accept me for who I am. I hope this will encourage other young people to put their hands up and say “yes, I have arthritis too and I am a young person”.

I will grow up with a positive attitude. I will accept the things I cannot change and do everything in my ability to change the things I can make a difference to myself and for others. Whilst all the people I have met, both young and old, through my experience over the past few years are sufferers of RMDs, I realise that, although we all have very common threads, our experiences of growing up or living with an RMD are unique to ourselves.

So, back to my 18th birthday – it’s going to be a mega celebration with family, friends and fun being the order of the night! I plan to dance the night away… In high heels by the way! I will probably pay for it for a week, but nothing is getting in the way of me having the time of my life.

Bring on the party!
Fernanda Ruaz, Portugal

My name is Fernanda Ruaz. 64 years ago I was born in Setúbal where I still live today. I have a son and two lovely grandchildren. The first onset of rheumatoid arthritis (RA) showed at the age of 10. I started working at 16 as a technical designer and later graduated in philosophy. When my condition worsened severely I had to retire at the age of 47. However, I continued to teach philosophy and write for regional newspapers.

In 1982, I was invited by my rheumatologist to join the list of founders of the Portuguese League Against Rheumatism, the current LPCDR. I decided to take part in the competition because I thought about the parents of children and young people affected by rheumatic diseases. Anxiety and fear about what the future will bring can hold back a lot of potential. Without seeing myself as a model for anyone, I'd like the 54 years I've already spent living with RA to bear witness to the fact that life doesn't have to be bad for those restricted by poor health.

Maria comes out of the hot shower, dries herself well and steps on the scales. No change in weight. Neither heavier nor lighter. Excellent. Now she's the ideal weight. She looks at herself in the mirror: lots of white hairs, a few wrinkles. “What do I expect? I'm a grandmother!” she thinks with a happy smile. A grandmother! Who'd have thought she'd live long enough to have grandchildren? She'd got it into her head that she'd live till 40, or maybe a bit more, and here she was already a bit over 60!

She gets dressed without difficulty. The new medicine had been much more serious. Sometimes she’d had enormous difficulty in having a wash in the morning, getting dressed, putting her shoes on and getting to work. And who would have credited that she’d be more mobile at 60 than she was at 12? We know nothing of what the future has in store for us. Nothing. That's what made the mystery of life so exciting for her.

Dressed and ready, Maria goes to the kitchen to make breakfast. The puppy jumps around her in little circles of happiness. “A good friend, this little dog, always happy with life. Why is it that humans are so often apprehensive? Why is it that humans worry so much and don’t get the most out of each moment? Shall we have breakfast, my friend? Your dog food for you, yoghurt, cereals and fruit for me”. She peeps out into the garden. The sky is blue and it looks like being a fine day. She can go out into the open air for her morning meditation. A few minutes giving thanks to life and to God; a few moments to organise the day.

“Why is it that humans worry so much?”

Today is going to be busy: she’s going to give two philosophy and two Portuguese lessons, but not until the afternoon. Tomorrow, a painting class in the morning and the afternoon is free... It’s good to vary the routine like that. Recently she discovered the pleasure of painting. Playing about with the paints, bringing colours to life... It’s good, so good, and takes no physical effort as long as she’s sitting properly and puts the canvas in a position where she can move her arms easily.

She’s followed scientific developments closely, always hoping the causes and mechanisms that result in the appearance of juvenile idiopathic arthritis would be discovered. That a miracle drug would come out and put an end to the torment of chronic pain and progressive deformity. And it’s true that a lot more is known now: lots of new pharmaceutical products, some of them extremely promising. Maria is sure that her trust in science, together with the quality of the medical support she’s received over the years, has helped tremendously to overcome the despondency she sees in many other sufferers. Being able to rely on a good rheumatologist, having a good relationship with her doctors and receiving high-
quality assistance have been vital for keeping her going. She simply can’t express the joy she feels every morning going out into the street and walking on her own feet. For many, many years, each step was difficult. She recalls how, as a teenager, she had terrible trouble getting up the steps on the bus. Now, at the age of 60, she goes up them with ease. How can she explain this? How should she express her gratitude for the prostheses, for those fantastic doctors? For the advances in medical science?

“There are things to discover every day”

Many times, so many times, she finds herself giving thanks to God for the amazement she feels. It’s true she’s had – and still has – many bad days. But it’s also true that she never thought she’d have so many good moments, days, months and years.

Many times she thought it was all over for her. When she found herself forced to ask for early retirement (although she’d worked for 30 years), Maria suffered a lot. A lot. Being at home all day was unbearable, but it was impossible at the time to overcome her inability to get onto public transport or tolerate being in the workplace for seven hours. However, “when we think everything is coming to an end, actually everything is beginning”. Just a few years ago, artificial knees gave her back her lost mobility and Maria looked for new challenges. It’s true she enjoyed reading, writing and listening to music, but human beings are social animals. Maria likes to communicate.

She started to concentrate on other people’s problems. She came out of herself and sought to demonstrate that there is hope, life does go on, new things are always happening and some of them can even be good. She devoted herself to an association for sufferers. She endeavoured to write things that would encourage others suffering in the same way. She made new friends, got to know some wonderful people and experienced new realities. She discovered that you can volunteer in many ways. Sometimes you don’t even have to leave home to help ease a problem nearby.

Maria accepted the challenge of giving free lessons to children and young people facing economic difficulties. “You must make the most of the gifts you have”, she often says. Teaching philosophy means making the effort to call everything into question, to see that there are many possible answers to some problems, and other problems that have no solution at all at the moment.

She’s happy to live in the era into which she was born. A lot has changed. Living with motor deficiency in the 21st century is completely different from being in the same position centuries ago. Today Maria has huge support from technology and the fantastic world of communications known as the internet. Writing or researching on a small computer is relatively easy, even for someone whose hands are very deformed. Freed from inflammation and with the pain lessened, Maria discovers every day that there are things to discover… To discover and share – and sharing is one of the best things in life. And there are also many things she gets from kindness, from culture and simply from everyday chats.

While it’s true her arthritis has improved, it’s also true that age and the continuous, aggressive medication bring other problems on top. Maria knows how careful you have to be if you want an active, happy old age. Keep a healthy mental attitude for a start. Don’t dwell on sad thoughts, resist the temptation to keep yourself to yourself. When you don’t feel well, go for a walk every day, stay in touch with nature, eat well… Cultivate friendships, be kind to other people, be kind to yourself, discover new possibilities. Being happy depends above all on affection. Crises – of whatever kind – can be tempered by love, tenderness and the cultivation of friendship.

Time! Maria knows that chronological time doesn’t stop. What’s important is to enjoy living in the present. While hairs and even wrinkles don’t make her sad. They are life’s trophies. Let the days roll on!

The young grow in height and knowledge, but the old, as Maria has learned, despite diminishing in size, can grow in wisdom!

“The old grow in wisdom”
My name is Ulrika. I am 34-years-old and I live with my husband Daniel and our two children, Jens and Sara in Halmstad, south of Sweden. Jens is six-years-old and Sara will soon be one. I got my diagnosis at the age of six. The disease has been very active and, in early years, I lost my sight. I love to read books and enjoy music. I am stubborn and, for the most part, happy. I find it easy to laugh and, my siblings tell me, I am fun-loving.

I’m interested in politics and social issues. I have studied from time to time, when my health permitted and when I had the strength. However, I have no profession. The disease has also turned me into tracheotomad, where I have a hole in the trachea. With my rheumatism and medications, it makes me very susceptible to infections. Soon it will be time for a couple of neck operations.

I learned about the Stene Prize through the magazine Reumatikervärlden. I like to write and thought I had a story to tell.

When I turned four, I got a wonderful birthday present – a little sister. My memories of that day are fragmentary. My Dad took me to a shop and bought me a red dress and a bag in the same material as the dress. Then we went off to the maternity hospital to see my mum and my little sister.

Two years later, my left knee swelled up. From then on, my life – and the lives of those dearest to me – was marked by illness, hospital stays, operations and a lot of pain. But there was also happiness, joy, a zest for life and a strong feeling of victory.

During the early years, my big worry was my eyes because they had been affected by rheumatism. I had one eye operation after another, and despondency would be followed by joy, only to give way to despondency once more. After four years of fighting, the disease had won the first round and I had become blind in both eyes.

In a way, however, I found it a relief – for then, at the age of 12, I no longer had to endure all those operations that I truly loathed. I was left in peace – for around two months.

Major inflammation developed between my first and second vertebrae, and eventually I was sent to London for an operation to fuse the vertebrae in my neck. The doctors in Sweden had treated me with shock doses of cortisone, but when my bone marrow was compromised and my life was in danger, they did the best they could; they sent me to a specialist who had already performed the same operation on 12 children all over the world. The operation was very successful, and I went from having to take morphine just to lift my head from the pillow to being left with nothing more than post-operative pain when I came round from sedation a few days later.

Many times over the last 26 years I have had to fight my way back. The one thought that has kept me going during the tough times is that the disease must never be allowed to win. I have lost my sight, I have become mobility impaired, I lost years of my childhood and youth; I can accept all that. What I cannot allow, however, is for my disease to rob me of my love of life and the motivation that drives me onwards. I have had to lower my sights over the years, but the feeling of having taught myself to find the bus stop and being able to get on the bus with my three-year-old son for the first time certainly bears comparison with the feeling of triumph someone else might experience on landing their dream job.

Several hospital stays and operations ensued during my teenage years. I would fight my way up, only to be knocked back down again.
When I was 24 I met my future husband, and one of my greatest dreams became a reality. It was one of those dreams that I had almost given up on for a number of years. Both my husband and I longed to have children, but that particular dream was much more difficult to achieve than I had imagined. From a young age I always had a strong desire and longing to start a family and have children. It was part of my vision for the future, you could say.

“One of my greatest dreams became a reality”

Rheumatism has left its marks; and not only the obvious ones – the fact that I am blind and have fused vertebrae. My growth was also stunted as a result of all the cortisone I was treated with. My bones have become brittle for the same reason. My doctors advised me against trying to get pregnant for a variety of reasons: it would be too great a strain on my body; I would be putting myself at far too much risk. That was the worst news I ever had to deal with. My future had turned bleak; I was filled with anguish and found it hard to sleep. Sorrow and despair gripped my soul, so to speak. I could not believe that rheumatism had robbed me of my future. After months of dread and despondency, I tried to haul myself out of the pit I found myself in. I decided to do my very best to get as physically fit as I possibly could and then take a chance on getting pregnant and having a child anyway. I had no choice but to try; that was just the way it was.

I underwent two operations – both my hips were replaced. After rehabilitation, I resumed my training programme in the gym, which I had started after commencing biologic treatment four years earlier. This medication had changed my life dramatically. I stopped taking the drugs that could be harmful to a foetus, and I ate to put on weight. I then somehow managed to put everything behind me, and hoped with all my heart that things would work out. Three months later I was pregnant.

After a wonderful pregnancy, I gave birth to our son in the 37th week. He is now five years old, and has a little sister of seven months. My second pregnancy also passed without complications, and my happiness and gratitude are indescribable. The decision to try for a baby was more difficult the second time around. I would be risking even more. I was, after all, a mother already, and obviously I did not want to get worse and be unable to look after my son as I had done up until then.

The yearning to have a child and to give our son one of the best things I have myself, namely a sibling, won the day. Today I feel great. My strength and fitness training means an awful lot to me, both for my body and for my mind. Even when I have relapses, and I have to start my training over and over again, I know that I am strong and that I can cope well.

I think the reason why I am able to live as well as I have done – and still do – despite a severe rheumatic disease has a lot to do with my outlook. I realise and accept that my illness and my functional disability affect my life, and I adapt to that. But I am always finding challenges and goals, and that stops me losing my spark. When I am obliged to endure tough operations and treatments, I challenge myself to bounce back as quickly as possible. It then becomes a kind of competition.

Keeping both body and mind as strong as I can in the situation in which I find myself – that is my strategy for life.

“I challenge myself to bounce back as quickly as possible”
Gabrielle Grosjean, Switzerland

My name is Gabrielle Grosjean, I am the oldest of three siblings, born a Swiss national to rural farmers on 13 May 1949 in the Moudon maternity unit. I have now been living for several years in Lausanne and have a daughter who was born in 1987.

I trained in general nursing and specialised in tropical medicine. I have been retired since November 2012 and have just enrolled on a training course for collectors of life stories, which will start next year at the University of Fribourg.

I got in touch with the Swiss League Against Rheumatism to enable me take part in a water therapy course in 2013. This is how I learnt about the Edgar Stene Prize. I decided to enter the writing competition because I like writing and regularly attend writing workshops. I hope that the story of my life could encourage others to follow their dreams.

My childhood was turned upside down by illness, and the adolescence that followed was a torment. At the age of six I contracted osseous tuberculosis (coxalgia) and then, at the age of 14, I began to suffer from pains which stopped me from sleeping. Walking became a trial. I was 15 when I had my first surgery for coxarthrosis. During this time span, I worked out how I would spend my life – as a nurse! When people close to me discovered this, each of them tried to dissuade me.

On the instructions of the insurance company, Assurance Invalidité, a group of experts on job opportunities evaluated my abilities. I was offered the choice between being a dental technician or a commercial clerk – two professions where I could stay sitting down! I opted for a commercial apprenticeship without giving up my initial choice. I learnt the job in a bank and cried a lot. Equipped with a certificate, I left to work in a hospital as a secretary in the personnel department.

One year later, I decided to leave everything behind and discover new horizons. A diplomat's family living in Cologne took me on as a young au pair to look after their two children aged four and six. It was hard work. I felt stable enough on my legs but the pains persisted, forcing me to snatch moments of relaxation and rest during the day. When my contract ended, I decided to test my endurance and abilities in a hospital environment.

"I felt like a top class athlete who had just won her first medal"

Obtaining work in a traumatology unit, I put on the white uniform of an auxiliary nurse for the first time. The work was demanding, and I was on my feet for more than eight hours a day. After work, I lay down to recover and relax my muscles. I successfully enrolled for training at the Lausanne nursing college. I had just a few more months of work before I could leave Germany. The experience of long and difficult days of rheumatic pain filled me with doubt and discouraging feelings. This stage was painful and, ultimately, I resigned myself to things. I wrote to the nursing college, describing the job as physically too difficult given my handicap. Very quickly, regret set in. I suddenly had the impression of giving in to my family and friends who were fiercely opposed to my plans. I had reverted to being an obedient little girl… I needed to grow up!

The nursing college received a second explanatory letter from me repeating my request to join their training course. I got a positive reply and I started six months later.

The college’s director was there for me, listening to and encouraging me. I benefited from extra time-out slots so I could rest during courses, which were physically wearisome. This woman gave me confidence in myself and allowed me to grow and blossom. The day the certificates were awarded was very emotional for me, and I was aware of the great esteem
felt by those around me.

One year later, I went to work for the organisation Terre des Hommes in Benin, Africa. I was one of three nurses. In a village out in the bush, far from anywhere, I worked without a break – sometimes for 24 hours at a stretch. For two years, we cared for the children, followed the pregnant women and delivered babies day and night in a shift system. We had one vehicle to enable us to evacuate sick people and pregnant women.

Africa made me grow up internally. The people accepted me and helped and supported me. One night, when the vehicle we were returning in broke down, I had to walk with the other passengers for more than five kilometres in order to get back to our centre. I arrived exhausted by this effort, paralysed by muscular tension and pain, but proud of having made it. I felt like a top class athlete who had just won her first medal! This experience gave me the courage to follow my goal.

“Pregnancy had impacted on my muscles and balance”

For 20 years I continued working as a nurse for different NGOs around the world. Those years were marked by friendship, love and human warmth, which allowed me to continue with my work. I came into contact with the suffering of people handicapped by war and illnesses. In their different ways, they all taught me to accept differences and not to throw in the towel or indulge in self-pitying.

When I became pregnant in 1986, I went back to working as a secretary in Switzerland so as not to put my body under too much strain. I demanded a caesarean so as to retain as much of my mobility as possible. My daughter was born one morning in January. I was so happy… The next morning, I could no longer walk properly. I was troubled with persistent pains. Pregnancy had impacted on my muscles and balance. I was breast-feeding my baby so there was no question of taking any medication. A friend suggested that I use clay compresses. After reading the literature on alternative remedies, I decided to change my diet. I became a vegetarian.

My daughter was two-years-old when I set out for Africa again. For another six years, I worked in the bush again in addition to being a mum myself.

In 1995, I returned to Switzerland and started work again as a nurse. I worked nights and then as a liaison nurse full time. This meant that my work no longer required physical effort since I dealt with advising patients when they left hospital.

A rigorously disciplined life and walking every day allowed me to perform the work of my choice without interruption, and allowed me to give and take. From time-to-time, I go to a thermal centre, I’m still a vegetarian and, since November 2012, I have been retired. My daughter is 25 now and is a physiotherapist.

Solidarity and the affection of my family and friends have been an indispensable source of support, enabling me to grow with a rheumatic illness. Today, I grow old in peace and contentment.

“They all taught me to accept differences”

Editor’s explanations:

Coxarthrosis is a type of degenerative arthritis of the hip

Traumatology is the study of wounds and injuries caused by accidents or violence to a person.

NGOs are non-governmental organisations.
How I face growing older with rheumatoid arthritis

Caroline Howson, United Kingdom

My name is Caroline Howson and I live in the small market town of Beccles in Suffolk with my family. I am 50-years-old, married with a son of 19 who is currently studying at university and a daughter of 16 who is at school.

I work part-time in a further education college, supporting students across the full range of abilities – from those with profound learning needs to students taking higher education degrees, providing support to those with educational, behavioural and access needs.

In my spare time I enjoy canoeing and walking with my family, and I love to travel. This year I am planning a trip to Morocco, where (RA permitting) I am hopeful that I will be able to do a little walking in the High Atlas Mountains.

I heard about the competition through membership of the NRAS and decided to enter. I have always enjoyed writing and, since diagnosis, have found myself with more time for this. I hope that by sharing our experiences we can benefit from the stories of others.

Middle age is often, traditionally a time to take stock of your life. Your children are leading more independent lives, the mortgage is almost paid off and you are starting to think about planning for the next stage of your life – with more time to enjoy the things you love. In my case this was a plan to enjoy more travelling.

I had dreams which included doing a “grown up gap year” – backpacking around India or South America perhaps – and looked forward to being able to enjoy walking and skiing holidays that were longer than a week or two. When I considered it, there seemed many positive aspects to growing older.

Nearly two years ago, although in my late forties, I considered myself to be very healthy, fairly fit and active. I enjoyed skiing and canoeing with my family, attended weekly boxercise classes, was enjoying learning ballroom dancing. I much preferred to walk or cycle into town, rather than take the car.

Then, suddenly, unexpected symptoms began: I stood up to get out of bed one morning and felt a terrible pain in the base of my foot. Gradually other joints joined in until, after about 10 months, a diagnosis of rheumatoid arthritis (RA) was confirmed and I was started on a treatment of methotrexate.

Others have described the journey of rheumatoid arthritis as like being on a rollercoaster and I could not think of a better description. Having to deal with a range of medical professionals on a regular basis, after rarely spending any time visiting a GP, was a shock.

“I have come to accept a new way of living”

Coming to terms with the language of inflammatory arthritis – all the new medical terms, different symptoms etc – was a steep learning curve. And accepting that I do have a long-term condition that is actually termed a disability, and have now become part of another group was the most difficult of all.

However, two years later I have reassessed my life and come to accept a new way of living – of moving into the future and getting older, with everything RA entails. I believe that, for me, the secret to dealing with this in a positive way is to accept the benefits of teamwork. To be able to live successfully with RA, I believe you need a strong, supportive team around you.

Firstly, I have had to learn to trust in the medical professionals who treat and support me. I have to accept that my consultant is the expert and take her recommendations seriously. Although I was extremely reluctant to take methotrexate at first (after having read many conflicting, often frequently terrifying reports), I accepted my consultant’s view that this drug was the best option to start with. I have found it to be very beneficial, with no real side effects to speak of. My GP and the rheumatology nurses at the hospital have always been on hand to offer support and guidance.

I was fortunate in getting quick referrals to podiatry, physiotherapy and occupational therapy services. As a result, walking is easier with shoe
supports, troublesome shoulder problems have gone away (even if only temporarily) and writing and typing are no longer the painful, difficult chore due to prescribed wrist supports. I have managed to carry on working in what can sometimes be a demanding job.

Other key “team members” have been fitness professionals. One of the key parts to being able to age healthily is to consider lifestyle changes. After first being diagnosed I did very little exercise and, as a result, this added to a feeling of generally being unwell. Instead of boxercise and canoeing, which both put too much stress on shoulder joints in particular, I had to find other forms of exercise which would enable me to keep mobile, fit and that I would enjoy.

“I had to find other forms of exercise which would enable me to keep mobile”

A friend suggested I come to spinning classes with her and, with the support of my GP who agreed it would be relatively low impact and a good cardiovascular workout, I started weekly classes. The beauty of spinning is that you can take part in a normal exercise class with people of all levels of ability and fitness, but you are able to go at your own pace. You can get a bike at the back of the class where nobody can see which gear you choose, knee supports can be worn unobtrusively under gym clothing and bikes can be adjusted to suit.

I was intrigued by a local advertisement for chair yoga and decided to try this as a way of getting some gentle exercise. Yoga was something I’d been meaning to try for years, but never got round to. I thought it must be fate when I discovered that the teacher had rheumatoid arthritis. What I couldn’t believe was the fact that she was in her mid 70s. Looking a good 10 years younger, and able to perform yoga postures I can only hope to achieve one day, she told me that practicing and teaching yoga had been a significant help to her in coping with RA.

I hope that with gentle yoga, flexibility and mobility will continue to improve, and equally important are the mental wellbeing benefits which arise from breathing and relaxation techniques. As yoga teacher and author BKS Iyengar has stated: “Yoga teaches us to cure what need not be endured and endure what cannot be cured”.

The support and help of others cannot be overstated. Family and friends have been a source of support and strength and have certainly done more than their fair share. But I would not have been able to understand the reality of living with RA without the support of the NRAS, and in particular its community support site. It has been a fund of information, advice and support from people who are in the same situation. Like many have said on the site, a true lifeline. Facing growing older with RA would have been a much more frightening prospect without this support.

Although there will certainly be many challenges to be faced, I go forward into 2013 with a positive attitude towards having RA. I know that, with the support of others, these difficulties can be faced and overcome. For out of every challenge an opportunity will arise.

“The support and help of others cannot be overstated”

Editor’s explanation:
NRAS is the UK’s National Rheumatoid Arthritis Society