EDGAR STENE PRIZE 2011
HOW EXERCISE IMPROVES MY LIFE WITH A RHEUMATIC DISEASE

eular Standing Committee of People with Arthritis/Rheumatism in Europe (PARE)
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 diseases. Within EULAR, the national organisations of people with arthritis/rheumatism across Europe work together and develop activities through the Standing Committee of PARE. For more information please visit www.eular.org

Contents

Editorial 4
About Edgar Stene and competition rules 2011 5
Meet the 2011 Jury 6
Interview with the 2011 winner from Norway 8
Winning essay 2011 9
Selection of essays 2011:
Belgium Flanders 10
Belgium Wallonia 12
Former Yugoslavian Republic of Macedonia (FYROM) 14
Iceland 16
Poland 18
Portugal 20
Sweden 22
Switzerland 24
United Kingdom 26
China – a contribution from the other side of the world 28

STENE PRIZE BOOKLET 2011

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The Standing Committee of PARE would like to thank all those who have contributed to this publication.
I am delighted to have been given the opportunity to write a few words on the theme of this year’s Edgar Stene Prize, “How Exercise Improves my Life with a Rheumatic Disease”. The great response we have had to this topic shows what an important role physical activity and exercise play in the lives of people with rheumatic and musculoskeletal diseases (RMDs). Walking the dog, going for a hike with friends at the weekend, dancing – physical activities are part of our daily lives, as well as being a big part of our social interactions.

The essays introduce us to a wide variety of different activities and are very inspiring to read. As a qualified physiotherapist, they give me a rare insight into what we, as health professionals, need to take into consideration when treating people with rheumatic diseases. Each patient we work with is different, just as each rheumatic disease is different, affecting people’s lives in manifold ways. In order to be effective and successful with our treatments we need to work in partnership with our patients so that exercise and physical activities can be incorporated into their daily routines as smoothly as possible.

In our busy lives this is not always easy, and with rheumatic diseases there also comes pain and fatigue. How can we motivate somebody who is in pain and tired after a long day’s work to still find the energy to take a walk or go to the gym? I think that national organisations for people with rheumatic diseases can play an important role here; and in many countries they already offer exercise classes and group training. As we can read in several of the essays, training with other people who have the same limitations has a positive impact, as well as offering the opportunity to socialise and exchange experiences.

There is also the fear of causing damage when exercising, so a lot of people with RMDs are afraid to join a sports club or gym as they do not feel safe. I can still remember the time when doctors and physiotherapists strongly recommended people with RMDs to rest and stay in bed in order not to aggravate their symptoms. Only slowly over time has an understanding of the benefits of moderate movement grown and demonstrated that in many cases, exercise can significantly improve people’s quality of life. Today there are a number of studies which show that exercise has many positive effects on people with RMDs, such as increasing flexibility and range of movement, improving balance and muscular strength, which are important to daily life and remaining independent. It is therefore important that people with rheumatic diseases have access to physiotherapists and other qualified therapists who can provide them with specialist treatments, training and advice.

I highly recommend the Stene Prize essays to everybody – including people who are not affected by RMDs. Physical activity is good for all of us and these essays help us understand that being able to move and enjoy physical activities are privileges which we all too often take for granted. The strength and courage of the essayists is admirable and their examples can not only help motivate people with RMDs to become active and to try different ways of exercising, but all of us. I would like to sincerely thank all those who have participated in the competition for sharing their inspiring stories and important testimonies to the benefits of being physically active.

Kåre Birger Hagen
EULAR Vice President Health Professionals in Rheumatology
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 into EULAR the “National Community Agencies active in the struggle against rheumatic diseases”. 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 (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 2011 Edgar Stene Prize

Every year the Stene Prize is awarded to the person with a 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 2011, entry was open to people with RMDs who are 16 years of age and over. Entries can be submitted in the native language of the author and EULAR has these translated 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.
Each year a jury is appointed to judge entries to the Stene Prize competition. Under the rules, jury members can only participate in the judging for two years running, so when the jury convened in the autumn of 2010 it was joined by new faces from Norway, Romania, Spain and the United Kingdom.

After the great success of last year’s Stene Prize, Marios Kouloumas, Chair of the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (PARE) and Neil Betteridge, EULAR Vice President, representing PARE, were very excited to be involved in the 2011 competition once again. As ex officio members of the jury, Marios and Neil do not take part in the judging, but use their experience to help guide the overall process.

Marios says about the Edgar Stene Prize 2011, “This competition gives people with rheumatic and musculoskeletal diseases (RMDs) from across Europe the opportunity to tell their stories. It allows others to read how they cope not only with the challenges of their condition, but the many barriers they face daily in accessing buildings and transport and dealing with the attitudes of society. This year’s theme focuses on the importance of exercise for people with RMDs and the physical and psychological improvements it can bring. The entries provide us with insights into how people with RMDs benefit from exercise and what kind of activities they choose to do. As always, the essays should inspire people with RMDs to exercise, motivate health professionals to encourage their patients to be more active and encourage policy makers to ensure people with RMDs have timely access to rehabilitation centres and facilities where they can exercise.”

“Exercise is one of the most important ways we can fight back against rheumatic and musculoskeletal diseases and help maintain our independence.”

Entries were sent to the EULAR secretariat by EULAR member organisations from Belgium Flanders, Belgium Wallonia, Cyprus, Czech Republic, Denmark, Estonia, Germany, Hungary, Iceland, the Former Yugoslavian Republic of Macedonia (FYROM), the Netherlands, Norway, Poland, Portugal, Sweden, Switzerland and the United Kingdom. Once again it was very difficult for the jury to choose the winner, as all the entries were of such a high standard. 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.
Alison Kent from the United Kingdom, an active member of the National Rheumatoid Arthritis Society (NRAS), chaired this year’s Stene Prize Jury. “Exercising is so important for everyone living with a RMD, not just because of the physical benefits, but also the psychological impact it can have. This is why I feel it is such a fantastic theme for this year’s Edgar Stene Prize. There are hundreds of different ways to exercise and this competition provides a brilliant opportunity for individuals to share their inspirational stories about the exercises that have worked for them and why,” says Alison, adding, “As a person living with rheumatoid arthritis, I am all too aware of the importance of motivating other people’s stories can be. Reading about the challenges people have overcome gives others the confidence and strength needed to try something new and improve their own life with a RMD. It has been a great privilege for me to be involved in this project.”

Alison was supported by four other voting members on the jury. The Standing Committee of PARE invited Professor Iain McInnes, rheumatologist and Chair of the EULAR Standing Committee on Clinical Affairs to join the jury for the second time. “Listening to patients forms a part of my daily activity as a clinical rheumatologist - but it is uncommon for us to have the opportunity to listen at a deeper level. The essays submitted in the Stene Prize competition are a rare and treasured opportunity to hear the true voice of the patient and to allow a considered reflection on the impact of their remarks. It is once again an honour to serve in assessing and learning from their teachings,” said Iain.

Codruta Zabalan from Romania joins the jury for the first time. She is an active member of the Romanian League Against Rheumatism and is also enthusiastic about this year’s Stene Prize theme. “I believe that it’s really important that people with RMDs do not just exist, but are able to live as fully and independently as possible. Being physically active is extremely important in keeping our joints mobile and our bodies functioning, but sometimes it can be hard to get motivated. I think the Stene Prize essays are really inspiring and show what can be achieved. So let me say thank you to everyone who sent us their story. Thank you for fighting, hoping, laughing, loving and writing about how you stay physically active. Thank you for living a wonderful life despite having a rheumatic disease, pain, stiffness and fatigue.”

The EULAR Health Professionals in Rheumatology were represented on the jury by Jenny de la Torre from Spain, who commented, “As a nurse I am very aware of the benefits of exercise. There are a number of scientific papers that show the relationship between exercise and improved outcomes for people with RMDs, which is why physical activity is considered one of our most important non-pharmacological therapies. However, I also listen to some of the difficulties patients have in getting started and finding an activity they can enjoy and stick with. I think the Edgar Stene Prize essays are a great way of motivating and inspiring people with RMDs to try something for themselves. This is one of the reasons why I have so enjoyed being part of the jury and to have had the opportunity to read so many wonderful stories.”

Also part of the Stene Prize Jury for the first time was Fatima Lavoll from Norway, representing the Norsk Reumatikkforend. “I must admit I loved the Norwegian contribution, but there were so many other moving essays of such high quality that I was still not sure which one had the best chance before the final vote. We are so thrilled that the prize went to Norway for the first time ever – I am sure Edgar Stene would have been very proud. As for the theme, for many years I was inactive and a bit scared to exercise, but with some good advice from my physiotherapist I started to exercise a couple of years ago. Exercise has really improved my life with a rheumatic disease. For me it is very important to exercise not just for my body, but also for my emotional well-being.”

After the great success of the 2009 and 2010 Stene Prize booklets, and the high quality of the 2011 contributions, it was decided to once again publish a selection of entries to share these powerful testimonies with a wider audience. The jury decided to add one entry to the booklet which was outside the regular competition. Neil explains: “It was a huge surprise and pleasure for the EULAR secretariat to receive an entry this year from China. The Stene Prize Jury was delighted to see that EULAR activities are now reaching people all over the world. Yan Yishu, 21 years old and living with ankylosing spondylitis, shared his story and insights with us. Even though this is strictly not within the regulations for the prize, we felt that we should publish this inspiring story from the other side of the world.”

“Clinicians speak and often patients listen; but when patients speak, everyone should listen! I commend these essays to everyone.”

“The Standing Committee of PARE would like to thank all those who contributed to and supported the 2011 Stene Prize competition and who have made this booklet possible,” says Marios Kouloumas. Professor Iain McInnes adds, “Upon reflection, I cannot remember a more emotive series of papers for review than those which I read in my participation on the Stene Prize Jury. Cincians speak and often patients listen; but when patients speak, everyone should listen! I commend these essays to everyone.”
An interview with Lill Due, 2011 Stene Prize winner

My name is Lill Due. I am a 36 year old woman. I am married, and live with my husband and three children in Bergen, Norway. I was diagnosed with Morbus Bechterew (ankylosing spondylitis) when I was 19 years old. I trained to be a teacher at the University of Bergen and I work part time at “Folkeuniversitet i Bergen”, where I teach Norwegian to adult foreigners from different cultures.

Last autumn (2010) I decided to become a member of Norsk Revmatikerforbund, (the Norwegian rheumatism – association). In its magazine I read about the essay competition and Stene Prize.

The topic of the essay inspired me to write. I loved dancing when I was younger, and I still love it in my heart. I bring this passion into my daily life. Living with pain is not easy, but you need to exercise to live life as normally as possible.

I wanted to participate in the essay competition because I like to express myself in words. I wanted others to read about my feelings and thoughts about my life with a rheumatic disease; the importance of training and exercises in helping to have a better daily life; even how hard it is to accept a life with a rheumatic disease.

What did you think when you heard that your contribution had won the 2011 competition?

Lill: I was so happy and felt very honoured to have been awarded this prize. I just couldn’t believe it, I thought I was dreaming! Many times that day I had to make sure I was awake. Even the following morning I had to ask my husband if I had really won, and he was delighted to confirm it was true!

What helped you the most when you had to accept that due to your rheumatic disease, your dream of becoming a professional dancer could no longer be realised?

Lill: It was very difficult to think about continuing my life without dancing. At first I was bitter, angry, and very depressed. But these feelings did not change anything; they just made it all worse. Ironically, what actually helped me in the end was ballet. I was used to doing ballet exercises until my toes bled, but not noticing the pain because of the joy of dancing. When I just wanted to give up on life because of problems with my hips, I just had to remember who I really was. I had to believe that I was more than a rheumatic condition. I felt as if the dance was still living inside my body, just like before. Inside, I had the same sense of humour; my feelings, soul and spirit were all still in there. I choreographed so many ballets in my head, and I danced them all in my mind. And the discipline I had learned from the ballet, to never give up, also helped me.

You write about the enormous discipline you learned from being a ballet dancer and how this kept you moving after your surgery. Are there any ballet exercises which you still find useful today and which could help others in the same situation?

Lill: Discipline and knowing my body so well helped me to start moving and doing exercises after the surgery. One of the secrets of becoming a good dancer is that all movements come from the centre of your body, the stomach pool all starts from these core (abdominal) muscles, lifting your arm or pointing your foot, the movements start from the centre. Having strong stomach muscles helps your spine and your posture, and your movements, balance, as well as improving your shape. This is very helpful for everybody, but especially for anyone who has a rheumatic or musculoskeletal disease or, like me, has a hip replacement or Morbus Bechterew (ankylosing spondylitis).

Over the past few years I have been doing Pilates exercises. This form of exercise is very popular with ballet dancers, because it strengthens the core support muscles deep inside in the body, especially the stomach and back muscles. Pilates exercises bring back the feelings I had when I was doing ballet, even though I can’t do all the exercises because of my hips. Still, this form of exercise is very good for people with rheumatic and musculoskeletal diseases as most of the exercises are done lying or sitting on the floor, which takes the strain off the joints.

What role does physical activity and exercise play in your life today?

Lill: Physical activity and exercise are very important to me. I do exercises in a therapy pool with a group led by a physiotherapist, and I do Pilates classes several times a week. I am afraid of becoming stiffer and worse than I already am. I really feel that exercises improve my life. As, step by step, I become stronger I can feel the difference and it is so good to know that my body can also be my friend.

How do you manage to integrate exercise into your working and family life?

Lill: It is important for me to be able to manage daily activities with my family. I work part-time as a teacher, which gives me enough time and energy to do my daily tasks, including exercising. Doing exercise is what makes it possible for me to be able to manage to work at all. Having children also keeps me active. Family walks in the park and playing together at the gym at the week-ends are all different ways of making me stay in as good shape as possible, in spite of my rheumatic disease. Also, my little daughter shares my passion for dancing and she likes me to teach her.

Is there anything you can think of that the Norwegian health system should provide to help people with rheumatic diseases to stay active and moving?

Lill: The health system in Norway is good. We have hospitals that provide intensive courses of exercise for patients, and the doctors and physiotherapists give out good information about the importance of doing exercises. Still, when the patient goes home there is nothing to motivate them to keep up their exercises. Also, there are waiting lists for participating in group programmes and, whilst you are waiting, it can be hard to keep exercising alone. I wish there could be more exercise classes for people with rheumatic conditions, as well as for different age groups. When people are first diagnosed, they need to be in a support group with people of their own age and with the same condition. Also, the long road to acceptance cannot just be achieved on your own. Doctors should also work more with psychologists, not just physiotherapists. It is very difficult to exercise when you are in considerable pain, or when you are feeling depressed. Everyone with a rheumatic condition needs special motivation to reach the final goal – exercising with a smile!
How exercise improves my life with a rheumatic disease

“Pas de chat! Stretch! Discipline!”

My French ballet teacher was strict. Strict and beautiful. She walked around with a stick and pointed at our feet if they weren’t perfectly stretched out.

“Stand up straight! Perfect!”

I worked out as much as possible as a child. When I danced I entered my own little world. My body lived a life of its own as I practically flew across the floor, “pas de chat”, in my pointe ballet shoes. I was flexible, elegant, lean and strong.

I achieved a fabulous self control and discipline. I needed to be in control of every nerve and muscle in my body to have the balance and strength to dance.

When I was 18 years old I danced as Cinderella with the Swedish Royal Ballet. When I was 19 years old I had become an ankylosing spondylitis patient living in constant pain. “Yes, you should be able to live your life as normal,” the doctors told me. “It’s important to exercise, but ballet isn’t suitable for you anymore. You cannot become a professional dancer, but it’s important to stay strong and flexible so that you don’t stiffen up.”

I worked out in the pool and went to physiotherapy. My life was turned upside down, but I could still move around. I danced in the pool, I danced on the inside. But I also cried when nobody was watching. Even so, I still had faith.

I hoped to one day be pain free, to have my old life back; to walk without a limp, to dance, to live without the pain.

“Unfortunately, there’s no other way. We have to replace your hips”, the doctors told me at the age of 24. I couldn’t quite grasp the fact. It was as if someone had hit me in the face. Hip replacement, prosthetic implants? Cutting into my muscles, hacking into my bones, inserting steel into my body? What about my ballet, my balance and strength to dance.

As I was standing there, in the hallway at the hospital, I felt depressed, anxious and scared. “Who am I now? Am I still the same person now that I have this disease? Am I still the same little ballerina who was so flexible and elegant and who could fly across the floor on the points of her toes?

Standing in the hospital corridor, holding on to my walker, it was suddenly as if a French voice was talking to me: “Pas de chat! Discipline! Stretch! Concentration! Keep it up!” I could almost sense the smell of sweat from the ballet room, and a soft tap from her ballet stick on my legs. I remembered how I always kept dancing, even when my toes were sore and bleeding. I closed my eyes and all of a sudden I knew that I was still the same person. I started to walk, one slow step at a time, and every nerve and muscle in my body obeyed, just as they did when I was dancing. Discipline! I practically flew down that corridor with the walker. Inside I was Cinderella dancing, on the outside I was a young woman with brand new hip implants.

With my newly discovered way of “dancing” I was inspired to not give up. I could feel that I was gradually gaining control over my movements.

“I was inspired to not give up. I could feel that I was gradually gaining control over my movements.”

Inside me I’m still dancing ballet as I do my exercises in the pool or with the physiotherapist. Without the self-discipline and self-control the ballet had taught me, I might have given up. But I will always keep on dancing, at least in my heart, even though I have a chronic disease and artificial hips. You can’t give up when you are in this situation, because if you do you will just get worse – become weak and stiff. You have to move, to find new ways to use your body so that it will function as well as possible. I’m still Cinderella; I’m just dancing in a different way. I dance my own “pas de chat”!
Ingrid Vandepaer
Belgium Flanders

My name is Ingrid, I am 48 years old and from Belgium. My husband and I live together in the little town of Kessel-lo.

I am a qualified physical education teacher, so exercise has always been part of my life. I found it a challenge to write about how I am learning to move again with my lupus, compared to how I was before.

I read about the Stene Prize in the ReumaNet e-newsletter. It attracted me because it involved writing an essay and for some time now I’ve been doing a lot of writing.

Being aware of your body and what causes tensions to accumulate helps you understand and accept your limitations. The balance between feeling good in your body and in yourself psychologically plays an important role in overall well-being. In the long term, being adaptable is important in helping you reach your potential and feeling comfortable in your body.

You can enjoy life again when you come to terms with the way you can move in your body. This is what I have tried to express in my essay.

How exercise improves my life with a rheumatic disease

The message ‘when the time is right’ appears on the screen of my computer and a light switches on in my head. ‘Get moving’ the flickering message says. I stand up and look for a point above my head. An imaginary string pulls the crown of my head upwards so my neck and back stretch out to the length they should be. I am very happy to experience this feeling; I stand and my body responds. My knees try to move and a little later I bend and straighten them. I can hear music in my head. My body thinks about dancing. Just a bit of movement and I feel alive again.

I am sitting at my computer as I write these words, and my inspiration is keeping the keyboard busy. I am going to get up for half an hour to exercise my joints, muscles and tendons. I need to do this because of the lupus in my body. I try to tame it so it will become like an obedient, friendly dog.

Pain and fatigue were also roaming around my body. I was becoming less and less able to move and more and more sensitive to pain. I was occupying a body in which I felt increasingly less at home. The kilos piled on. After work in the evening, I would collapse exhausted into an armchair and then wouldn’t be able to get out of it again. A day with large groups of children who were running around and full of energy completely drained me.

I was asking a lot of myself; too much and it can hurt: An inflamed joint in the shoulder, fingers that were difficult to bend, knees that were refusing to take part in the rat race any longer, a pelvis that increasingly tilted my back and unbalanced me.

“My knees try to move and a little later I bend and straighten them. I can hear music in my head. My body thinks about dancing. Just a bit of movement and I feel alive again.”

I wanted to teach them about the value of keeping active throughout their lives. But the children instinctively knew something I was increasingly forgetting – don’t stay sitting in the same position for too long, move about and, when the time is right, try and take a little rest. That’s what these clever children were telling me every day. Yes, I have to acknowledge that a child has a highly developed sense for movement. There I was thinking I knew it all, but I was forgetting about my own situation.
I have had to put an end to my teaching career, but the fun that children experience when they are active is a lesson I am careful to put into practice – because all too often, I was trying to push myself too hard. Now I’m trying to rediscover the wisdom of children for myself. Now I am a prudent student, learning slowly, step by step, walking day by day back to a body in which I can live freely and at ease with myself.

“I enjoy being in the swimming pool and feeling the water passing over my skin.”

“How am I doing?” I ask myself whenever I am waiting for the bus. “How well am I getting around when I have things to do in the town? Could I arrange my body comfortably when I lie on my back and feel pain? I’d better not stop here, even though my right leg starts to tingle when I’m cycling.” Slowly I am becoming aware of my capabilities. I can do more and more now without sapping my energy, because I am turning the tiger inside me into a cat that first stretches its paws and then starts to walk.

I enjoy being in the swimming pool and feeling the water passing over my skin. With the smile of a dolphin I slip through the water and marvel at the ease with which I can move. Being in the heated pool with other swimmers with rheumatism provides a warm and relaxing environment. We meet in an oasis where we respect each other and gradually, acknowledging the limitations of our bodies, we can learn to adapt our movements. Here we are not judged. Here, everyone moves to their own music.

Just as children in a gymnasium explore different ways of moving around using their own abilities, I keep moving; rediscovering the lightness and the ease of childhood movement. This is what I am now programmed to do.

“Being in the heated pool with other swimmers with rheumatism provides a warm and relaxing environment. We meet in an oasis where we respect each other and gradually, acknowledging the limitations of our bodies, we can learn to adapt our movements.”
Mens sana in corpore non sano

Quand, comme moi, on est atteint
De maladie rhumatismale
Notre vie et c’est normal
Prendra un tout autre chemin.
Il est impératif d’abord
De s’accepter en tant que tel
Avec comme règles nouvelles
D’autres limites pour son corps.

Le sport est une aide précieuse
Dans ce dosage perfectible
Entre une rémission possible
Et ces douleurs insidieuses.

D’abord pour ces valeurs morales
Qui permettent de se dépasser
Et de sans cesse renouveler
Les forces de notre mental.

Ensuite pour le bien charnel
Que vous donne l’excercice,
Sans fard et sans artifice,
De toute activité corporelle.

Il faudra être raisonnable
Dans le choix des activités
Pour, sans payer les pots cassés
Construire un programme acceptable.

Nous pourrons, et ça c’est certain,
Abandonner le marathon
Comme objectif de la saison
Pour pratiquer d’autres terrains.

Quand l’occasion sera présente,
Privilégier quelques longueurs,
Au bassin pour une petite heure,
Pourra être moment de détente.

Traverser au petit matin
Sur un sentier de randonnée
Une romantique hêtraie
Vous mettra le coeur plein d’entrain.

En solitaire ou en peloton
Sillonner nos chemins Ravel
Dans nos campagnes éternelles
Vous regonflera les poumons.

Simplement devant la télé,
Suivons des yeux l’animatrice
Et copions tous les exercices
Sur un rythme toujours endiablé.

Dans le sport et la maladie
Nous retrouverons excercées
Les valeurs enfin acceptées
Qui rendront plus belles nos vies
Le courage et le don de soi,
De ses limites l’acceptation,
L’entraide et la satisfaction
D’avoir été au bout de soi.

“Dans le sport et la maladie
Nous retrouverons excercées
Les valeurs enfin acceptées
Qui rendront plus belles nos vies.”

Philippe Wanufel
Belgium Wallonia

My name is Philippe Wanufel.
I am a married father of five children and grandfather to six grandchildren. I am 53 years old and have had rheumatoid arthritis since I was 43. I used to teach the Catholic religion, but because of my illness I had to take early retirement. Now I keep busy with voluntary activities like Altéo (voluntary service for Christian mutual insurance companies), and working as a “Hopiclown” (a hospital-based clown) and a Patient Partner (medical education programme). I belong to the CLAIR association, and this is how I found out about the Stene Prize. I decided to take part first, because I love writing and secondly, because this year’s subject really appeals to me personally. I was always a very sporty person and studied sports techniques as part of my Humanities course.

I played football, rugby and was very keen on jogging, mountain biking and any other form of sport. I took part in the first two BaRIE cycling events to Barcelona and Paris. I believe strongly in the value of sport for any illness.

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Comme objectif de la saison
Pour pratiquer d’autres terrains.

Quand l’occasion sera présente,
Privilégier quelques longueurs,
Au bassin pour une petite heure,
Pourra être moment de détente.

Traverser au petit matin
Sur un sentier de randonnée
Une romantique hêtraie
Vous mettra le coeur plein d’entrain.

En solitaire ou en peloton
Sillonner nos chemins Ravel
Dans nos campagnes éternelles
Vous regonflera les poumons.

Simplement devant la télé,
Suivons des yeux l’animatrice
Et copions tous les exercices
Sur un rythme toujours endiablé.

Dans le sport et la maladie
Nous retrouverons excercées
Les valeurs enfin acceptées
Qui rendront plus belles nos vies
Le courage et le don de soi,
De ses limites l’acceptation,
L’entraide et la satisfaction
D’avoir été au bout de soi.

“Dans le sport et la maladie
Nous retrouverons excercées
Les valeurs enfin acceptées
Qui rendront plus belles nos vies.”
A healthy mind in an unhealthy body

When rheumatism struck, one fine day,  
Coming from nowhere, out of the blue  
It changed the way I saw myself,  
And made me appraise myself anew.  
What once was normal for me to do,  
Was now beset with limits for my frame,  
New rules, new standards replaced the old  
Made me accept I am no more the same.

Sport comes to our aid in many ways,  
A sort of medicine to stave off the pain  
It lets me hope for some remission,  
But then the aches creep back again.

First, sport is for those moral strengths  
That help you do your best and more,  
Help renew your mental powers,  
And face whatever lies in store.  
Also good for bodily well-being  
And gives freedom from restraint  
Gives movement and aids exercise  
Without pretence, disguise or feint.

You have to be reasonable, realistic  
In what you choose to do  
So you do not suffer consequences  
Make a programme that is good and true.  
No marathons any more for me  
There is no doubt, it stands to reason  
Need to find other roads to go,  
Some other way to fill the season.

Sometimes the opportunity presents itself,  
To enjoy the water in the pool,  
And swim some lengths for a little while  
Relax and stretch and keep cool.  
Or take an early morning walk  
Through fields and take care not to miss  
The romantic beech grove  
Which fills my heart with bliss.

In a group or on my own  
Following the country paths and ways  
In our eternal countryside  
To which I sing a hymn of praise.  
Sometimes I watch the TV trainer  
Doing exercises on the screen  
Which I copy as best I can  
At a pace that’s fast and mean.

In both sport and sickness  
We rediscover those things of worth  
Which make our life more beautiful  
And make us happy and give birth  
To courage and a sense of self,  
To acceptance of our lot in life  
To mutual help and the satisfaction  
Of finding our true selves through strife.

“Sport comes to our aid in many ways,  
A sort of medicine to stave off the pain.”
EDGAR STENE PRIZE 2011
HOW EXERCISE IMPROVES MY LIFE WITH A RHEUMATIC DISEASE

My name is Pavlina Pejkovska; I am married and the mother of two beautiful children. I took my university degree in philosophy in Skopje. I had a happy youth and a good job as a journalist, albeit freelance, but due to poor health I was forced to leave that job. I am a professor of philosophy, logic and ethics by occupation, but it is hard to find permanent work. Life has blessed me with making a family of which I am proud. However, I was taken ill with an insidious and harsh disease about which I knew very little. I am now undergoing treatment and am feeling better. Although at first I found it hard to come to terms with my new situation, I made the decision to fight my condition. The information I received from my doctors, written materials and internet articles have encouraged both me and my family to persevere and not to lose faith in life. I found out about the Stene Prize competition on the topic of ‘How Exercise Improves my Life with a Rheumatic Disease’ on the Internet.

I was dreaming of blue, transparently clear water. A boy was playing a lyre and a pair of white swans were singing a song.

I woke up with my hands as heavy as lead and as painful as the absence of light. I was sitting alone in the silence of the night, afraid that I might wake them up again, my dearest children. The swans! I remembered. The swans of Apollo used to sing the most beautiful song before dying. Was this a warning? Fear of death? Words that would remain unsaid?

For five years, pain in the night has been my companion. Nagging, abusive, intrusive pain... I’m not ashamed to admit that I cried. I cursed the day I was born. All right, I said, a hand, a leg, a knee may hurt... but to hurt all over! That’s unfair.

“Mum, why are you ill every day?” Ane has been asking all these years with tears in her eyes. She was only six years old when I became ill. Struggling to contain his tears, Gjorgji, who was soon to turn nine years old, asked, “Mum, is this our fault?” I kept explaining to them that the fault lay with my body which was no longer able to do as I asked, and that I was not looking after my health. The stress was to blame for everything.

I had devoted my youth to preparing for a beautiful, stylish and emancipated future. Because of the post-socialist transition, my philosophy degree was no longer relevant. I wasn’t able to find a job and I lost my independence. Mental pain turned into physical pain and together they led to a state of depression. Falling ill was inevitable.

Because of the intensity of the pain, at times I would run out of patience and start shouting at my small, sweet, innocent children. Then I’d feel so guilty and cry. I hated my helplessness.

Today, Ane is 11 and Gjorgji is almost 14. They have spent many sleepless nights because of my condition, even though they needed that sleep in order to grow.

The swans brought me back to the true reality of my spirituality. I’ll leave them to sing and I’ll fight without crying.

“Drugs alone are not enough! Exercise!
Salvation lies in physical activity; in finding and doing exercises that are appropriate to my physical abilities.”
As a patient at the Rheumatology Clinic, I have made sure I seek advice on how to improve my health.

**Drugs alone are not enough!**

*Exercise*! *Salvation lies in physical activity; in finding and doing exercises that are appropriate to my physical abilities.*

The first step was to get rid of the morning stiffness in my hands and legs. I tried to separate my stiff hands from my body. You have to exercise to get your body moving. My right hand has always been the faster to release, and so I tried using it to lift my left hand. I managed to extend them forwards and then backwards. I let them drop down to my legs and then raise them up again. I was speaking to the sun, looking for wisdom in life. Light, heat, cosmic energy, love, will... These are the natural positive phenomena that must be respected; the enemies of destructiveness.

I would then fold my hands together and join them in front of my heart, in a PRAYER to the Creator. “God, give me the strength to transform pain into tolerance. Give me back my smile so that I can make my children happy. Move my hands every day to the rhythm of some lively music. Give me the will to function normally.”

Every day I did my hand exercises. I would open my palms and stretch my fingers in a fan. I felt every joint. I would repeat the exercise several times up to the moment when my muscles began to shake. The pain would recede gradually and my faith in my fingers was restored. I was able to feel them again and to hold objects firmly in my hands without them slipping out. In my garden I dug a few flower beds and planted violets, carnations, strawberries, cherry tomatoes and chillies. That made me tired, but I was proud of what I could achieve with my hands.

The hardest part of all was restoring the strength to my legs and getting rid of the swelling and painful cramps. I felt the pain most severely in my hips. I could feel it moving up my body, from my pelvis all the way up to my fingernails. My face would contort with pain and my children would look at me all confused. Every morning they helped raise me and sit me up in bed. I had no strength to stand up. My legs would give way. I noticed that warm water helped me a lot. Moving my legs in water and doing exercise became my morning ritual. I felt better.

Before I became ill, I would spend weekends mountaineering and strolling along the bank of the river Vardar. I didn’t want to say goodbye to the habits I enjoyed and I set myself the task of walking a few steps more each day. Eventually I returned to the river bank. One day I managed a 10 km walk with my husband; I was over the moon. I soon began climbing to the top of Vodno mountain (1060 m). The first climb was the hardest for me. I could feel pain moving from one joint to another. My muscles were shaking, but my husband and children wouldn’t allow me to give up. Every time we returned home, with a mixture of fatigue and joy I would admire the colours of my garden. I started writing poetry once more. *My children’s future is what inspires my poetry and my struggle against rheumatoid arthritis. I hope I will continue walking down the path of my life, slowly but surely, with a heart full of love and gratitude for my family.”

“My children’s future is what inspires my poetry and my struggle against rheumatoid arthritis. I hope I will continue walking down the path of my life, slowly but surely, with a heart full of love and gratitude for my family.”
My body, my responsibility

Thuridur Helgadottir
Iceland

My name is Thuridur and I live in Borgarnes, a small village which is a one hour drive from Reykjavik on the west coast of Iceland.

I am 49 years old and work as a social and healthcare assistant. I read about the Stene Prize in the Icelandic League Against Rheumatism’s magazine. As I love writing this was an exciting challenge and I decided to take part. As I wrote in my essay, I love hiking and enjoying nature in Iceland’s beautiful landscapes. I have already climbed to the top of Hafnarfjall, a mountain of 844 meters high, more than 60 times and there is always something new to discover.

Three years ago I started exercising, mainly going jogging with people from the runners’ site. I took up jogging with enthusiasm and positivity and followed a routine devised for me by an established site member. But things didn’t turn out quite as I’d expected.

Despite my good intentions I wasn’t that good at it and I ended up straining some of the muscles in my feet. The worst pain though was in my pelvic area, which is the weakest part of my body. “Pelvic wear-and-tear” – that’s how my doctor described what was to become my travelling companion for life. Every piece of imaging equipment available confirmed the diagnosis.

I have always been keen on exercise, mainly going to organised gym classes, so I couldn’t really be accused of being a quitter. Of course, the jogging idea was really just a fantasy, because my body wasn’t actually able to support me. I may also have been in denial about my limitations, which is something most people struggling with this condition can probably relate to.

If I were to try and give you a rough idea of what it feels like on the occasions when this companion of mine plays up, giving me arthritic symptoms, I would say that it is similar to the pelvic dislocation you can experience during pregnancy. The only difference is that I can’t break free from my prison after the nine months are up. The disease is in my pelvis and, when I put my body under strain, the pain extends to all my pelvic joints, lower back and groin. I get swelling and knots in my thigh muscles, which feels a bit like driving along the roads in the Icelandic countryside which are ridden with potholes.

Despite this sob story I have just given you, I am still able to do a lot of things. Instead of jogging, I now use my trainers to go hiking, rather than just putting them away on a shelf. This is an acceptable solution because I really enjoy hiking on gravelly soil and heathland, and even on hills. However, this is still a form of weight bearing exercise that strains all my joints, so my willpower often caves in because of my reduced levels of stamina.

Swimming, of course, is the best thing for arthritis, as the water supports your weight and eases the load on your joints and ligaments. That’s why I feel virtually no fatigue after going for a swim. I go swimming twice a week, for an hour at a time, and I do one and a half to two kilometres. Sometimes, my battery runs down halfway through the exercise session and I just have to accept that. We all have off days. Five or six years ago all I was able to do was breaststroke, but with endless practice, good teaching and tenacity I have managed to master all the other strokes as well. Flippers, floats, goggles and

Thuridur
my physiotherapist, I decided to sorts of pelvic floor exercises with condition at the time after doing all dancing and was in fairly good for zumba classes. Since I love Last winter, I saw an advertisement best thing for course, is the “Swimming, of joints is essential. cycling can be hard on the joints gel-padded saddle, because cycling can be hard on the joints in your groin. When I go cycling outdoors, protective clothing for my neck, shoulders and all my joints is essential.

“Swimming, of course, is the best thing for arthritis.”

Last winter, I saw an advertisement for zumba classes. Since I love dancing and was in fairly good condition at the time after doing all sorts of pelvic floor exercises with my physiotherapist, I decided to give it a try. I had not been able to do general exercise of any kind for a long time. I did zumba twice a week; I was almost the oldest in the group, but I managed alright, given all my limitations. Even then, I obviously felt the strain in my groin and hip area and, when I came home, the only thing I could do was have a shower, lie down and get some rest. Sometimes, I needed extra painkillers, but it was definitely worthwhile taking them. I ended up doing various forms of exercise to fun music and in good company. To be on the safe side, I wore a good pair of trainers and a belt to support my lower back. Many people thought that I might be taking this exercise thing too far. I did actually hear some of them say “You? Going up hills and hiking out in the wilds? Huh, you can’t possibly have arthritis, can you?” That was a really prejudiced comment, as if they could possibly know what it’s like having arthritis!

Today, I do an average of 30 to 40 minutes exercise a day. I put that down to what I said before, which is that keeping fit comes with certain limitations when you suffer from the conditions I do. It is only just over half of what I was able to do five years ago.

After I have finished my fitness routine, I do 10 to 20 minutes stretching, focusing on the muscle group that has taken the heaviest strain and on my weakest areas. Stretching, exercises, massage and other treatments and routines prescribed by my physiotherapist are all part of my training regime, as are hot tubs, water massage and relaxation. All of this takes a lot of time and tries my patience, but I still think every moment is worth the money. If, the day after exercising, I can wake up with only relatively little pain, then I am ready to do the same things all over again.

I’ve worked in geriatric care for many years and am always reading about ways to improve health and physical fitness. On the back of all that, I’ve learned that there are various tools and tips which can improve my well-being, as well as that of other people. I am lucky, in that I have a good doctor, physiotherapist and occupational therapist who I can turn to when my symptoms are getting the better of me. I have found the work they have done with me and their encouragement invaluable.

I still think my willpower has to be the number one factor behind my success; my sense of personal responsibility and self-esteem are what help me get through my day-to-day exercise routine. I’m grateful for what I have and what I can do, and I’m trying as hard as I can to use it to my advantage.

Although I am aware of the side effects that these drugs can have, I have decided to take anti-inflammatories regularly, and have also needed injections for my arthritis to get rid of the swelling and joint pain. The combination of these treatments enables me to be more active in my work, my studies and when exercising. The pleasant fatigue that I get after these different activities helps me sleep well every night. Like other people with arthritis, I too have had bad days when no drugs or treatments seem to work, and even days when I have been unable to do any work. I remember having days when I would mope around the house, miserable, depressed and gloomy, when I would lock the door and crawl into bed like a wounded animal. These are memories I’d rather forget. Running a marathon, breaking sports records or spending my whole day in the swimming pool will probably not be included in my list of accomplishments; that’s just the way it is. And I know for sure that at some point I will have to stop going out for challenging walks and hikes. I’ve had to pay dearly to be able to do them and it will be difficult for me to continue. Eventually I will simply have to make do with looking at the path up the mountain slopes that I can see from my window and fantasising about the view and the freedom that climbing up there and meditating can give you.

“See the top, that’s where I climbed.” My closing words are from the poem “Mountain Walks” by Tómas Guðmundsson

“I still think my willpower has to be the number one factor behind my success.”
My name is Brygida, I was born in Opole and have lived there for 50 years. Opole is a medium-size town in the south of Poland, near the borders with the Czech Republic and Germany. I trained as a nurse and that is my passion. My grown-up children, daughter Waleria and son Aleksander, often come to visit our family home where I live with my father and my dog Fiona.

I have many and diverse interests. I still have the curiosity of a child and an enormous appetite for life. I am constantly searching for answers to the many questions I have, so I love reading. I read about the Edgar Stene Prize competition in 2004 in ‘Złoty Środek’, a magazine for people with rheumatic diseases. Every year I write something for the competition, as I would like to play my part in spreading the good word. If my experience can help improve the life of even one other sick person, then it is worth writing!

CHILDHOOD
It was a time of carefree play. We seized every opportunity to play with friends in our street: chases, races, roaming through fields and woods. In winter, it was tobogganing, skating and making snowmen. In the summer, I was always on the move with a ball, on a bicycle or running around on my own two legs!

SCHOOL
Racing to school on our bicycles was brilliant for fitness. Our PE teacher at school was passionate about sport and we won volleyball and handball tournaments. Running was my favourite. At the end of primary school, I had quite an array of certificates and a few medals. I could have taken sports at secondary school, but I chose biology and chemistry, as I wanted to be a nurse. After all, I had already practised nursing on my teddy bears and dolls.

ADULTHOOD
I lost my passion for sport in the serious business of becoming an adult. Under the pressures of daily life and responsibilities, I forgot the joy that movement can bring.

“I will not do these boring exercises! It’s still hurting and the illness hasn’t gone away!”

ILLNESS (Rheumatoid Arthritis)
I watched with awe and envy shop assistants moving about and the number of steps they took. After cryotherapy, moving without pain is a miracle for me! But saying goodbye to high heels is an emotional blow.

AND THEN
I alternated between grief and rebellion: “I will not do these boring exercises! It’s still hurting and the illness hasn’t gone away!”

AND SO IT WENT ON
Making detailed plans for a number of activities, ensuring there was sufficient time and I had enough strength and resilience to endure the pain. The big problem with this is that the worse I become, the more I plan and the less I do.

THE MILLENNIUM ASSOCIATION
We learn exercises for people with arthritis from Hania Zechowska of the ‘Association for People with Rheumatism and their Friends’ in Warsaw. It’s easier in a group. We’re ambitious, so we meet in a gym and a specialist supervises our exercises. Then a momentary lapse in concentration, an unlucky fall and I have a fractured lumbar vertebra. The group doesn’t give up. We arrange to exercise in a swimming pool, we do Tai Chi and we go Nordic Walking. However, all these activities have one problem in common; they are occasional and, over time, attendance falls. It is difficult to adapt group activities to the current state of health and capabilities of each of the participants.

SHOES
I have a collection of shoes selected not by choice, but by necessity. Deformed and painful ankles are quite a challenge. Orthopaedic shoes are the worst. Sports shoes are best.

Edgar Stene Prize 2011 How Exercise Improves My Life with a Rheumatic Disease

Brygida Widera
Poland

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SHOES
I have a collection of shoes selected not by choice, but by necessity. Deformed and painful ankles are quite a challenge. Orthopaedic shoes are the worst. Sports shoes are best.
I have long forgotten about high heels and the fact that the style of the shoes does not match my clothes and I look terrible. All that matters is to be able to get out of the house and to where I am planning to go. Unfortunately, it seems that in winter disabled parking bays become the best places for dumping the snow that has been cleared from the roads!

**SURPRISE**

I open my eyes, the sun is shining outside and I can hear the birds singing. Everything is in motion. Clouds float serenely across the blue sky, the heels of pedestrians clack on the pavement and a car drives by. I extend my left arm from under the warm duvet. It’s worth leaving the lovely warmth to greet Fiona. She has been living with me for a year. She has the softest multi-coloured coat, large, attentive, wise eyes surrounded by long eyelashes, a wet black nose and ears that stick up. All of this topped off by a curved, bushy tail, four paws and a body that’s… just the perfect size! Fiona is a great bundle of joy and activity. Fate has given me the best possible aide to getting an obstinate person like me moving again. I have no trouble reading Fiona’s signs when she’s asking:

- Throw me the ball, and again, and again!
- Come and play with me in the garden!
- Time for a walk now. It’s time!! Come on!! Stop whinging, there’s no escape. You know you love me!!

Yes, I love her loads. I want her to be happy, to forget that someone threw her out into the street when she was a tiny defenceless puppy. So I throw the ball and play in the garden like a child. I go for walks and I can’t wait for spring and summer to come when games and walks are the longest and the most interesting. Life is just wonderful with my little Fiona puppy as my companion.

**DESPITE THE ILLNESS**

Is it possible? How has a tiny mongrel done this?

I know, I remember from my childhood. It’s simple! Life is motion. I’m moving, so I’m happy with life, despite my illness.

“Fate has given me the best possible aide to getting an obstinate person like me moving again.”
Life without exercise...

It almost seems like a joke. Life plays tricks on us and frequently puts us to the test, too frequently! Just when everything seemed to be quietening down, I was confronted with the words Scleroderma, Systemic Sclerosis, CREST Syndrome... But what did they mean? What was this disease? Chronic, incurable, and progressive... which can leave my face expressionless, my hands stiffened, with wounds that will not heal, skin lesions, pulmonary fibrosis, difficulty in swallowing... fatal... help!

I do not want to know any more. I just want to know why my hands are freezing, as white as wax and hurt indescribably when I catch a cold, or get very upset... This is not what I wanted! I had set myself a goal. I was following a dream that was about to become reality... I still wanted to be a spinning instructor, to go on teaching. At last I knew what I really wanted to do, and now they tell me I have a rare disease that is serious and incurable, which can progress, turn me into a dependent person, take away my mobility! What about my children? I want to see them grow up; I want to help them with their homework; I want to experience their first loves, Andre’s first shave, Carolina’s first period... this cannot be true!

The first reaction is always to think the worst. There is always too much information available to us, and filtering out what is “good” and what is not becomes complicated and wears you out. So I got on with my life, got used to the medicines, accepted what was happening to me, learned to deal with the pain (so often bearing it in silence), and endured all the discomfort, for which at least there was now an explanation. It was not my paranoia as I had thought for so long.

I cried; of course I did, and I still cry a lot. It is hard to accept this reality and deal with those around you when you know you have a “companion” forever. You tend to think that, sooner or later, you will become a burden to someone. You cannot help thinking that in certain situations you will constrain the lives of those...
Spinning class

around you, and that people will feel sorry for you; it is horrible! It is very difficult to come to terms with what has happened to you. Realising that not everything needs an explanation is the first sign that you have finally begun to accept that you have something you must learn to live with for the rest of your life, not with sorrow and defeatism, but by being very strong. You also realise you must try your best to learn from both good and not so good experiences; to overcome all your challenges so that ultimately you feel you can help others benefit from your experiences, which can often be simultaneously both full of suffering and rewarding.

I am often forced into thinking “Why me?”, as if “someone” has set this path for me. Maybe because they thought that, because I am so strong, I would be able to “deal” with everything with a smile on my face, always trying to win and never giving up. It was what stuck with me when I learned that my father was ill and would not be able to spend much more time with us. I think a lot about the years he was ill, knowing that there was a last day with strength, hope, and being able to stay the same, although, of course, with certain changes. But deep down I am very, very well. I finally found a doctor whom I trust and believe in. I feel confident in the treatment I am receiving and I am confident about the future. As I told my children, never give up. We may take longer to do things and may do them less well, but never say, “I cannot do it!”

Exercise will continue to be part of my life as it is crucial for my equilibrium. And although my life is very intense today, I know that I will gradually have to begin to slow down when the fateful day comes. Thinking about it makes me live each day with strength, hope, and trying to be happy.

Power to us all! Never stop fighting; we can do anything! "Never stop fighting; we can do anything!"
How exercise and training can improve one’s life situation
A dialogue: between the body and mind of a person with RA

Björn Friberg
Sweden

My name is Björn, I am 58 years old, and have lived with my rheumatic condition since 1993.

My second wife and I live in a house by the ocean, a couple of miles north of Gothenburg. I have two grown up children from my first marriage and my wife has three grown up children from her previous marriage and we spend many happy hours with our eight grandchildren.

When I was young my favourite subject at school was athletics and I played football and handball. I was even a trainer and coach. So when I was diagnosed with my rheumatic disease it hit me hard.

I have always tried to live in a balance between denial and acceptance although if I’m honest, I am always more inclined towards denial; “When I wake up tomorrow, everything will be fine.”

I have recently become a member of the Swedish Rheumatism Association. It was in their magazine that I found a little article about writing an essay on improving life for those of us living with a rheumatic disease.

This essay is written as a conversation between a “healthy brain” and a sick body.

After a restless night and waking up several times, the brain eventually decides to tell the body to get up.

Brain: “You may as well get up. Besides, it will soon be half past six.”

Body: “I know that – I can’t lie still any longer anyway, but you know I’ll complain about it. You know that as soon as I have to exert myself to get out of bed I will be sending you pain signals.”

Brain: “I know, but if you move about for an hour then it will get easier, and you won’t complain as much. Surely you want to get to work on time today.”

Body: “Don’t you understand what I’m saying? Why don’t we lounge around a bit and sit on the sofa and perhaps watch a good morning show on TV instead. I feel I need to relax. We could have a little discussion about how, if we could just stop nagging one another and try to accept our differences, you could stop disagreeing with me all the time.”

Brain: “You can’t just give up like that – you know that work brings health and prosperity. You need to work and exercise, and for that matter you need to eat more healthily too. Then you will function better and have a good life, just like everyone else.”

Body: “In that case, first and foremost I need to have the time and energy to train and exercise before I can do my work. How and when do you think that’s going to happen? You know that after a day at work I’m completely worn out, and I don’t hear any complaints from you in the evenings either because you too are tired after work. As you know very well, just getting dressed and going to the bathroom every morning is a difficult exercise for me.”

Brain: “But you get pills, a drip and support to help you manage better. This isn’t overdosing, you know. When you can control this properly, you can function extremely well.”

Body: “We’re not just talking about exercising to cope with the job, but how to improve all aspects of life. Isn’t life more important than work?”

Brain: “Well, maybe. Last summer, when we were on holiday and there was absolutely nothing we had to do, you were quite relaxed and went on walks to look for mushrooms and swimming without any major complaints. You also liked cooking on the barbecue, having a lager and generally being sociable when your friends and kids dropped by. You even managed to play with your grandchildren. We did stuff together. We had a really good quality of life then, and we were happy and felt good.”

“We’re not just talking about exercising to cope with the job, but how to improve all...”
aspects of life. Isn’t life more important than work?”

**Body:** “That’s exactly what I call quality of life. I know we can have the happiest times of our lives when we are on the same wavelength. On holiday I was more physically active than normal and you weren’t always nagging me about all the things that had to be done.

“Now I have had to give up most of the physical activities I enjoyed because of my illness. I have had almost all of my leisure activities, such as sport, football and handball taken away - things I used to do for myself so I could manage to work in the first place. We have also virtually stopped doing creative things like music; you know that I see playing the guitar as exercise for my fingers. And the other things we used to do for myself so I could have several files full of exercises. After a couple of appointments, when the therapists don’t have any more they can tell me, they recommend I do my own exercise programme. I have had annual membership to the gym and swimming pools for exercise classes, swimming and aqua aerobics. When I’m there I don’t feel completely uncoordinated on the dance floor.

“I’ve been to physiotherapy, and I have several files full of exercises. After a couple of appointments, when the therapists don’t have any more they can tell me, they recommend I do my own exercise programme. I have had annual membership to the gym and swimming pools for exercise classes, swimming and aqua aerobics. When I’m there I don’t hang around with the fit, beautiful, athletic people, but on the other hand, I feel too healthy to be with those people who are seriously affected by their rheumatic diseases.

“I went on a rehabilitation trip to the sun, which was paid for by the local council, something people should find out about. Following the trip I felt better than I had for years, but after a few weeks back at work I was as bad as before.

“Everything I do is exercise for me, and I am happy when I just manage to dress myself, or when I succeed in taking care of my personal hygiene by showering or going to the toilet without asking for help. I used to manage this better when things didn’t have to be done by a certain time. You know that I don’t like to be stressed.”

**Brain:** “I have thought about all this and have come to the conclusion that you can sometimes become very blinkered. You, Body, and I, Brain, can’t each lead separate lives. This will only lead to arguments all the time. After all, we have a family of loved ones to care for and a wonderful spouse, who we both love more than anything, and that is the most important thing in life. So we can’t just keep moaning and complaining as soon as things start getting difficult.”

**Body:** “If we look at ourselves, when you talk about your quality of life you often forget all the essential things that have to be done. We rarely have the time and energy to both feel good at the same time.”

**Brain:** “Okay! We know one another really well, so perhaps we can come to an understanding that we are both needed when it comes to choosing whether we want to be happy and feel fine. I’m well aware of what you would rather do and I won’t nag you about how you want to go about your training and exercises in order to take part in life, and I won’t say, ‘It won’t work’. But neither can you say, ‘It won’t work’, to my ideas.”

**Body:** “I know what you mean. If I push the boundaries a little and exercise and train more than I actually feel like, and try to be the best I can, then perhaps you can also help and support me so that I can spend more time joining in with the things our loved ones are doing, even if it does hurt sometimes.”

**Brain:** “That’s exactly what I mean. If you can learn to listen and distinguish between when I am joking and when I am being serious, accept my humour and train as much as you can, then I promise to be more conscientious when I try to guide and encourage you. Then you’ll know that I don’t mean you any harm, but just want to raise you to a level that we can both call, a good quality of life!”
“Pain won’t kill you!” my doctor told me in his cheery yet comforting tone. “You have to keep moving”. That gave me a wry smile. Six o’clock in the morning: That infernal alarm clock on the bedside table goes off and forces me to lift my arm. “Stop. Enough. Don’t move!” my body shrieks. My brain tries to overrule it. The toilet flushes constantly: The 14-year old has won the race to the bathroom. My husband shuffles around the bed and opens the door. The dog bounces in, slobbering all over me and wagging his tail, eyes alert and wanting something to happen. The 17-year old still needs lunch for school and the eldest catches an extra five minutes sleep on the loo, until the waiting father flushes it. Mercilessly, the daily routine gets me going and my brain tricks my body-programme into booting up.

How exercise improves my life with a rheumatic disease

There is a delicious aroma as hot coffee flows into my favourite cup, just as a cold dog’s nose gives me a nudged reminder. Two trusting eyes testify to the fact that only in the utmost emergency would he have an accident in the house. For all the love and attention we provide, a glance out of the window from our four-legged friend is enough to make us feel guilty! But the healthy dog will not give up and, groaning, I struggle to put on my rain trousers. In playful anticipation he bounds back and forth and I wish that I had just a fraction of his strength and energy. Despite the wind and the weather he drags me out to engage in canine gymnastics: down on one knee to scoop a poop, standing up again being careful with my back, then rushing down the road and watching a squirrel mesmerised. Back at home I allow him to retrieve all the socks from under the eldest’s bed as a reward. Contented, the dog disappears off to his basket for a nap, and I am envious.

I drink the now cold coffee and restore some sort of order to the kitchen. It’s a relief that I am able to move more easily now.
than I was two hours previously. A glance into the bathroom is enough to turn me rigid again and the sight of the kitchen floor convinces me not to have any visitors that day.

A glimmer of light remains. In the afternoon my angel will arrive. For six years she has cheerfully breezed through our house and saved the family from domestic meltdown. It took a long time before this investment was recognised as being vital. She does all the activities that are not good for me, leaving me more time for therapeutic exercise.

Yesterday it was Bechterew water gymnastics, tomorrow it will be a long walk with my friend and the dog ... daily movement is undertaken without question.

A glance at the clock and I am back on track. The Pilates class is shown in red on the calendar. Regular participants chatter as they get ready in the changing room. A friend mentions that she has already had to take aspirin twice this week. To avoid embarrassment I give an understanding nod and spare her my list of daily medication. These pills stop me from seizing up and allow low-pain movement. Somewhat more stiffly than all the others I am able to do the “nasty five”, “teaser”, “boomerang” and the other exercises, and then I treat myself to a trip to the steam room.

Back in my kitchen control centre a selection of vegetables is cooking in the automatic steamer and the potato gratin is sizzling in the oven.

Organisation is – almost - everything.

Lunch eaten, the washing-up left undone, I snuggle blissfully under the blankets. Uninvited, the dog darts into my bed.

In one hour my angel will arrive and the home delivery service will drop the grocery order at the front of the door.

In my control centre my Kenwood mixer will knead dough for fresh bread. Oh yes, and the dog...

An active life allows me to stay mobile and, thank God, this illness is not going to kill me.

“Yesterday it was Bechterew water gymnastics, tomorrow it will be a long walk with my friend and the dog ... daily movement is undertaken without question.”
My name is Matthew Moulding, I am 37 years old and from the United Kingdom. I am married and currently live and work in Switzerland as an IT consultant. I heard about the Stene Prize from my mother, who saw it promoted on the Arthritis Care UK web site. I had been considering writing about my experiences and sharing them with others with my condition, and this opportunity galvanised me into doing just that.

Exercise had always been an important part of my life. At 18 years old I was a professional footballer and at 35 I was still going strong, mountain-biking 2,000km down the length of Great Britain.

But in the space of four months, after I had finished my epic cycle ride and returned to my desk-bound IT work, my undiagnosed condition of nearly two years went into overdrive and reduced me to a shell of the man I was before. I endured sleepless nights of excruciating pain, followed by days of yet more suffering, culminating with anxiety about the tortuous nights that lay ahead. Within a year of being diagnosed I was making my wife, my brother and a good friend redundant and closing my company that I had spent 10 years building up, as well as delaying starting a family because of the medication I was taking and my lack of income.

It felt like my whole world was falling apart, not just my body. But one year on and two years since my diagnosis, I’m free from pain-killers, cycling up Swiss mountains, working out daily, and looking to get back into the same level of work I did before. Exercise does not just help improve my life; it has helped me reclaim my future.

“Exercise does not just help improve my life; it has helped me reclaim my future.”

My name is Matthew Moulding, I’m 37 years old and in December 2008 I was diagnosed with Psoriatic Arthritis - asymmetrical polyarthritis affecting me from head to toe; in my feet, hips, groin, back, neck, jaw, hands and, coming along for the ride, some very strong fatigue.

According to the Kübler-Ross model there are five stages of grief: denial, anger; bargaining, depression and acceptance. If applied to my situation, I spent most of the first 18 months bouncing between denial and anger, only very briefly dipping into bargaining. As far as I was concerned, acceptance was simply not an option, but mentally and emotionally this created a heavy load for me to carry around.

During a routine appointment to see one of my doctors in October 2009, he asked, “How are you coping with not feeling indestructible anymore?” As I tried to answer, “Not very well...,” I simply burst into tears as the reality of openly admitting it overwhelmed me.

But physically I reflect back on my stubborn refusal to look acceptance in the eye as a key factor in my rehabilitation. I recognised very early on that my pain and discomfort were always worse after inactivity, especially first thing in the morning after a night in bed. Clearly I had to go to bed at some stage, but I resolved to do all I could during the day to help myself.

In the very beginning, “exercise” just meant trying to get some dexterity into my hands and normally this first routine of the day was performed under the hot water of the shower. This progressed to a weekly Monday morning visit to the local hydrotherapy pool, in which I would do some more extensive stretching with the water taking all the strain from my joints, and after a few months I would often go for a cycle round the village.
at lunchtime. By the time the summer came I was able to do some good long off-road rides, albeit thanks to co-codamol, which I was still taking regularly to take the edge off my pain. During this time I also started to do strength training with some free weights at home, and although there was often considerable discomfort and increased pain at the outset, once I got through that I could sense the improvement.

After exercising, my range of movement was always better. Although, for what seemed an eternity, I would wake up each morning back in the same situation and have to start all over again to get mobile. But I knew that if I could motivate myself to exercise, my day would be better for it.

Each session was a victory for me and a defeat for arthritis.

I still take the opportunity to swim whenever I can, even though I’ve never liked it as a sporting activity. I’ve found the best uses of the sea or swimming pools are for doing stretches or cooling off after exercising. As with all forms of exercise, what one does before and after can be just as important. My favoured routine is to get my joints mobile through exercise, then reduce any inflammation with cold water before warming up my body again with a hot shower. Having a hot bath just makes things worse. With arthritis, what you don’t do is just as significant as what you do.

A further benefit of exercise is to keep me generally fit and healthy so that since I started taking a biologic agent, and was exposed to the increased chances of infection, I have remained defiantly resistant, thus helping me to continue my recovery.

Exercise is not the only reason for my recovery, but it has played a vital role and continues to do so in the ongoing management of my condition. The battle is won, but the conflict continues. Arthritis does not rest, so neither can I.

I started by saying that exercise had always been an important part of my life. It was. And still is. Hopefully it will be for a long time to come.

“It’s about how hard you can get hit and keep moving forward. How much you can take and keep moving forward. That’s how winning is done!”

Rocky Balboa, 2006

“Each session was a victory for me and a defeat for arthritis.”

Choice of exercise was crucial and I learned quickly what forms of exercise were beneficial (low impact ones like cycling, swimming and using a cross-trainer) and those that would actually make things worse. Running has been out of the question from the very beginning and still is, even though I did try during a particularly belligerent few days of denial and anger. It’s bad enough for the joints of a healthy person, let alone someone with an inflammatory condition!
My name is Yan Yishu and I am 21 years old.

I am studying in ZhengZhou, HeNan Province, which is in central China and is the birthplace of Chinese medicine and ShaoLin Kung Fu. My major subject is clinical traditional Chinese medicine and I am in my third year. I want to tell others how I manage my ankylosing spondylitis by doing exercise and how I have improved my sports life in spite of my rheumatic disease. I want to share my experience and happiness with others.

Yan Yishu
China

My hometown is Dalian, a beautiful seaside city famous for football.

I had a happy childhood. I liked to swim and play football when I was in middle school, but in 2005, when I was 15 years old, my right leg was injured whilst playing football. I thought it was just a pulled muscle in my leg, but within a month things had become much worse, even though I had physiotherapy. My right hip swelled up and became extremely painful. I could not play football anymore and a year later I was diagnosed with ankylosing spondylitis and HLA-B27 positive at the Beijing Union Medical College Hospital. In the beginning I was sent to many large hospitals all over China, but the experience of going to big hospitals can be full of highs and lows. Sometimes, I had to fly to other cities alone in order to see doctors. When I got off the plane I was unable to walk so had to use the wheelchair offered by the airport.

Whilst I was ill I read many medical books and researched the latest western advances in treating ankylosing spondylitis in order to be able to work better with my doctors. I am eagerly awaiting advanced medical treatments, such as stem cell transplants.

Now, however, I am very well and am an ordinary university student, but I believe something miraculous has happened to me. I have many courses to study, I keep doing physical exercise nearly every day to prepare myself for the changeable weather between autumn and winter. For the past two years I haven’t had to take any medicine for my ankylosing spondylitis.

“This year the jury decided to add one entry to the booklet which was outside the regular competition and received by the EULAR secretariat from China. The Stene Prize Jury was delighted to see that EULAR activities are now reaching people all over the world. Yan Yishu, 21 years old and living with ankylosing spondylitis, shared his story and insights with us. Even though this is strictly not within the regulations for the prize, the jury felt that it should be published as it is an inspiring story from the other side of the world.”
This summer, I swam as far as 5,000 meters out to sea and I also gained my national social swimming instructor’s certificate. I also took part in a big Tai Chi and Kung Fu show held by my university.

Having a sound mind in a sound body is always a good thing. The combination of my knowledge, being physically active, medicine, acupuncture and Chinese health philosophy helps me recover when I am ill. To keep my body in good condition, I am careful about the food I eat, getting enough sleep, relaxation and being physically active.

“This summer, I swam as far as 5,000 meters out to sea and I also gained my national social swimming instructor’s certificate.”