EDGAR STENE PRIZE 2009
RARE BUT NO LESS SEVERE:
THE CHALLENGE OF COPING WITH A RARE RHEUMATIC DISEASE

eular Standing Committee of People with Arthritis/Rheumatism in Europe (PARE)
It was with great pleasure that I received the invitation to write a few words on the theme of this year’s Stene Prize: ‘Rare but no less severe: the challenge of coping with a rare rheumatic disease’.

Given the rapid growth of EULAR, which includes the integration with PARE, amongst other initiatives, EULAR developed a strategic plan for 2008-2012. With this plan we have defined where we want to go and with what priorities. With a relatively large group, we formulated objectives for where we want to be in 2013.

The Standing Committee of PARE would like to thank all those who have helped to make this possible. We especially would like to acknowledge the cooperation of the Norwegian League Against Rheumatism and the Norwegian Rheumatism Association and their endorsement of the Edgar Stene Prize. The committee was elected by the representatives of PARE member organisations in one of the official languages of EULAR (English, French and German). EULAR also covers the cost of travel to the Congress of the winner attending the ceremony to receive their prize.

Rules of the 2009 Edgar Stene Prize
The Edgar Stene Prize is awarded every two years to the best essay submitted by a person with a rheumatic disease describing his or her individual experience of living with their condition. Entries are submitted to the Standing Committee for Rare Diseases in one of the official languages of EULAR (English, French and German). The member organisation then selects the best entry to forward for judging by the EULAR Standing Committee of PARE, with the winner being announced in their newsletter.

The Edgar Stene 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.
The 2009 Stene Prize Jury

"Hemingway once said that there was nothing to writing, that all you did was to sit down at a typewriter and bleed."

According to the rules, and in order to make a fair judgement of all sixteen entries submitted, an official Stene Prize Jury was appointed by the EULAR Standing Committee of PARE in September 2008.

Maarten de Wit, EULAR Vice-President representing organisations of people with arthritis/rheumatism and Sandra Canadelo, Chairperson of the EULAR Standing Committee of PARE, were among the seven jury members, both ex-officio and with no voting rights. Maarten and Sandra were both excited about the Stene Prize and agreed that it is an important initiative as it addresses peoples’ hopes and dreams, their good and bad times.

Maarten says: “Some scientific researchers claim that writing can heal people with severe illnesses. I believe that writing down autobiographical stories or personal experiences can soothe the mind, not only of the writer, but also the reader. The power of acknowledgement might be stronger than the terror of ignorance or denial”. And Sandra adds: “Hemingway once said that there was nothing to writing, that all you did was to sit down at a typewriter and bleed. That’s a good way to put it - the people who send in their applications are brave enough to share their innermost feelings, their personal experiences, their sorrows, their victories, the very essence of their lives and their core as human beings”.

Maarten de Wit, the leader of the jury, said: “This year’s theme is of such importance that I was sure we would get a lot of insight and learning about the experiences of people living with a rare rheumatic disease. I think the Stene Prize is very useful in many ways as it raises awareness about different aspects of rheumatic diseases and helps others in the same situation”. Four other members supported David in fulfilling his task. Anna Dalosi from Greece says about her work as a Jury member: “Being part of the Jury for the Edgar Stene Prize was both a great honour and a remarkable experience. All the essays provided me with substantial knowledge on the way the authors adjust to the reality of living with a rare disease; the way they cope with the emotional and social implications and the way they maintain their quality of life. It is important to remember that even though the diseases are rare, the people who have them are many and, in any case, are assertive enough to grasp the opportunities they deserve as equal citizens.”

Jack Skrolsvik from Norway feels the Stene Prize is very important in improving the relationship between doctors and patients: “Many people with arthritis/rheumatism find it difficult to verbally express their situation and needs to others. They feel other people think they are self-obsessed.” However, writing an essay represents an alternative form of communicating as others – including doctors - can read it when they want to. And the Stene Prize is all about relations between patients and doctors. I am therefore glad to see that so many people used this wonderful opportunity to tell their story.”

Jury member Ovidiu Constantinescu from Romania adds: “Writing gives you the chance to bring out your most inner experiences; your pain, your fears, your hopes and moments of joy. Your condition - as rare as it may be - is no longer inside but outside you. It can be confronted, befriended, laughed at or simply lived with. The Stene Prize gives you the opportunity to take the first step in that direction, a chance not to be missed.”

Sesilie Halland from Norway was very impressed by the quality of the entries received and the messages shared. “The essays gave a very good picture of what it’s like to be diagnosed and live with a rare rheumatic disease in Europe. Some of the stories were heartbreaking and others were very positive. Many of the entries could have won the prize as the authors had very good writing skills.” says Sesilie.

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An interview with Emmi Myöhänen, 2009 Stene Prize winner

Emmi says she is an optimistic realist - “I’ve grown to understand realistic possibilities and choices, but I tend to think almost everything in a positive way”.

For a 19-year-old girl that implies a great deal of time putting life into perspective. Having been diagnosed with Juvenile Linearic Scleroderma when she was six years old, Emmi is about to graduate from upper secondary school this spring and hopes to be leaving out of home followed by university studies at Helsinki University of Technology. At the moment she lives in the south of Finland with her family - her two younger sisters, her mother and father. In her free time she dances, swims, goes jogging and spends time with friends and her boyfriend, just like any other girl of her age. We asked Emmi a few questions to get to know her better.

What made you send your story as an entry to the Stene Prize? What did you think when hearing about having been chosen as the winner?

Emmi noticed the announcement and thought she could write something for herself, without sending it to the contest. But after reading the story my friends were so insistent I send it that I just had to do it. I didn’t take the whole thing too seriously and I was so surprised when I realised how big it has grown. I’m going to Copenhagen, meeting the award, the booklet, etc. My first thought after hearing about my winning was, that there was probably no-one else participating and I still hope not totally taken in what’s really happening.

What do you think are the means to be able to still fulfill the dreams people have after the onset of a chronic rheumatic disease?

Emmi: Having the right attitude is the key to everything. The support of friends and family is important but, after all, every sick person has to go through the fight alone in their own head. People should take more care of themselves and each other.

What main changes do you think should happen in society to create a better life for people with rheumatic diseases, in particular for young people?

Emmi: When you’re young and have a disease like me it’s hard to make plans for the future. It would be important for young people to know what kind of career jobs they could make and, of course, ways to contact each other. When it comes to rare diseases, more money for research is always needed.

We know that you are an active member of the Finnish Rheumatism Association - what is the main benefit of being involved in such an organisation?

Emmi: In general, the information you get is the most important thing for me. I’m also the Secretary General of the Finnish Scleroderma Association and meeting other people with scleroderma has been very interesting.

Any message for our readers/young people?

Emmi: Remember to smile: It takes only 17 muscles to smile, but to make an angry face you need to use more than 40.

If you want to hear more about Emmi, please go online to http://www.epasen.net and or http://livingwithsclero.blogspot.com.

My rare condition

The pianist plays the first bars on the record. The soft voice of the teacher in the background, I turn to the bar. I let my hands breathe in the opening, then place them delicately on the bar.

The first position, demis-pié... ...and releve, demi-pointes... I loosen up; the body knows what it’s doing. Thoughts are wandering somewhere else.

Bend your right arm over the head... ...same with the left...

Suddenly skin refuses to give and movement stops for a fraction of a second, as if this tension came as a surprise. I feel how the bulge of ribs becomes visible when the skin tightens around them. My left side can barely do half of what the right side just did.

The third position, demi-pié...

The skin on my armoire does not give in either. It has tightened even more since last week. In the mirror, I can see everyone else doing the movement with the greatest of ease while I sink into desperation for a moment. It’s not the potential I lack. As I lose more and more of my ability to move, I wonder what I am even doing here. I’ll never become a ballerina.

I’m supposed to have an appointment with the specialist, big decisions ahead. To try out new medication or not? To let the tightening of the skin limit my daily life or to face the heavy side-effects of another course of drugs? Can the spirit of a small person handle the psychological consequences of the disease progressing, without even trying to stop it?

I can’t help but feel a little jealous. How many teenagers need to concentrate on something like this during a ballet class? At times it feels like the sickness doesn’t leave room for any other thoughts, as if there weren’t a single moment for me to breathe freely, as if I always had to strategise my life like a war. The doors are open for the healthy, scleroderma closes mine.

And the leg slides to the floor... Left shinbone knocks nastily onto the hard floor; the already bruised knee will be bruised again tomorrow. At moments like these you understand the importance of fatty tissue. Such self-evidently, many of us have too much of it. I, though, have none.

They say a sick person usually feels loss when their illness takes something important, like health, away from them. It also makes them lose many other things from their everyday life. Some are little, some are big and important. Not only do I lose my fatty tissue, but with it go my looks, my energy, and those innumerable opportunities I used to have... ...port de bras away from the supporting leg...

A large movement with the arms, back extending slightly backwards...

The vertebrae of the spine crack as the back bends and the shoulder blades slide in pain. The thought of loss still bothers my mind. Haven’t I also received something good out of this? I wonder how much specific knowledge and maturity this condition has brought to my life - understanding, prioritising and apportioning? The darkest clouds make us find the brightest silver linings, and those things are what make a person smile. How many smiles would I have missed without all of this?

Neither the amount of patience nor the support and caring of those close to me have shown me can be measured by any known indicator.

Rise up again, hands back on the bar.

The open window brings a fresh autumn breeze into the room. Breathing it feels wonderful, but at the same time I feel my fingers slowly turning pale while the coldness sneaks into them. Vains contract, blood doesn’t flow. Bit by bit a pinching ache has reached every finger.

Maybe that’s what positive thinking is all about, trying not to think only about loss? In the end, what we have here is only on loan. None of us leaves this world in our body, no matter how healthy or sick you’ve been. If nothing is truly ours, do we deserve anything more than we get?

Tendu to the right... ...pas de de temps...

I sigh silently when I feel the sharp pain in the soles of my feet. Only yesterday I thought I could ask the teacher to help me to buy ballet shoes. Maybe I could feel like a ballerina for a moment, before scleroderma ruins my chances of doing it. But what would I say to the teacher, how would I back up this thought? How to explain succinctly and comprehensively to an outsider everything that scleroderma involves in a way she would understand, when I haven’t even been able to explain it all to myself?

Back to the first position, lower your hands, and the music ends.

I look in the mirror. My natural look will live beats the desperation, concentration returns to the room. I see a good posture, a smiling face. I see a person who despite the hardships enjoys her life to the fullest.

That moment I make the decision never to let scleroderma keep me from dancing. I decide to focus on the doors that are still open to me, not to the ones that have been shut already.

There’s potential in me to do almost anything and I won’t give up any chance to use that potential.
Living with polyarthritis

I dedicate these few pages to my family, to all those who suffer from a rare illness and to all those who are fighting an internal battle, whatever it may be!

It all started when I was 6 years old. I often wondered "But why me?" and then the next day I would dismiss this thought. For everyone, life is a long journey interspersed with phases that need to be overcome.

I recall my childhood and the village where we used to live, as well as our house, which was located at the end of a very narrow alley. There was a little area with fruit trees, the walnut trees near to a heap of sand where my brothers and I loved to play and those narrow passageways behind the fir trees where we used to slip off to play hide-and-seek and which gave us the feeling of being in secret passages.

Then, one day, my brother Théo fell seriously ill. My other brother and I didn't appreciate straightaway how serious it was. I can no longer say exactly when this took place, but it is etched into my memory. On that day, I had some very bad pains in my arm! The next day, there was a skin test at school and my mother thought that I didn't want to go to school because of that. But I was really in a bad way because some spots had appeared on my body. The spots disappeared but other pains made their appearance, and that was only the beginning. I wasn't able to continue going to the gymnastics class – I had to watch the others.

I heard my father crying with my grandfather in the corridor. It was the first time that I had heard him cry. This man that was so big, so strong: why was he crying like that?

Then I couldn't run anymore, so many of my friends no longer wanted to play with me. Finally, there were bad times when things were critical, I couldn't walk anymore and my mother had to drive across the school playground in her little car, then take me in her arms and support me into the classroom. In the eyes of my classmates, I was changing into someone different. I saw lots of them keeping their distance from me. Then I had to leave them to receive my medical care. The words of the doctor still echo in my head – "She'll have to be admitted to hospital." I wept, I didn't want that. And I stayed there for two months which seemed to me to be an eternity. I had to try all sorts of medication for them to find one that reduced my pain. I saw my parents every day, but was already losing touch with my former life – I was ill. When I went back to school after this interruption, I had to face change once more. The difference in me was becoming more and more noticeable. I felt and suffered the ridicule of the others, or their indifference. My body was transforming little by little, I was in pain, and my joints were swelling. I was still friends with some of the girls, but I couldn't play the same games anymore.

Today, the illness is still there, though it is not as aggressive as it was. It has left me with serious after-effects, but thanks to medical progress, to a bit of will-power and to a very good circle of friends and family, I am happy.

Laurence Hastir
Belgium
My name is Laurence Hastir and I am 34 years old. I've had juvenile rheumatoid polyarthritis since I was six years old. I have a partner and have just had my first child, a little girl, who is only two weeks old. I am a graduate of the Academy of Fine Arts in Mons and I love painting in my spare time. I live in Molinwez, in Belgium. The disease has not overtaken with me yet. Every day I have a constant battle to complete my tasks and to realize my dreams and those of my partner and our little family.

I have participated in the Stone Prize contest because when writing about this terrible disease, which affects very young children, I am able to share my experiences and hope to help other people affected by it and their families. At the same time I hope that this might also influence and motivate doctors and researchers to find new approaches to treatment.
Living with a rare disease

Health is the greatest gift a person can have and they should celebrate it everyday of his or her life! Unfortunately, health is usually only appreciated when it is lost. Something similar happened to me six years ago. Something I took for granted was suddenly taken from me. Below, this is how my story begins.

I was in front of a doctor who was announcing something that was difficult for me to take in... He said that his diagnosis of what was happening to my body was scleroderma. Being a Greek speaker, I understood from its definition that this disease had to do with hard skin, which was not correct. He explained to me that it was a serious chronic and also rare disease that I would have for the rest of my life. He presented me with a list of bad things that could happen to me, but consolad me by saying that with good cooperation between us we could control it, as there is no cure for it. I was speechless and panic-stricken, just watching him talking. In the end, the only thing I asked was, “Will I die soon doctor?”. He smiled at me and answered that I could continue my life with some limitations from now on, but I could cope with it. I left his office in a state of shock, and in despair. I could see my life from now on full of pain, misery and disaster. Although my family and friends were, and always have been by my side, still I wondered how I would support myself and how I would be able to be independent again.

I found out that having a rare disease was a lonely situation, so I needed to meet other people with the same problem. The only way to do this was to become a member of an association, which is what I did. There, slowly but surely I found myself again. I started to gather information about the disease, because an educated patient can really help himself. Then I recognised that there was another thing I could do. Being optimistic and positive was the best treatment I could offer myself. No other option was permitted. I was determined to allow the disease only the smallest space in my body. Initially, though, I had to come to terms with it. This was the most difficult part, because you have to accept the new situation, and stop asking “Why is this happening to me?”: You just have to accept it and focus your energy on improving your health, rather than wasting it on something you cannot change.

Meeting people with the same disease helped me feel I was not so alone after all. As few as we are, many other patients face the same problems or even worse. Sometimes, by supporting others, you are supported in return. Being involved with the association also gave me the opportunity to travel abroad. This was another thing that broadened my perspective. New experiences, new attitudes, new places! Although the reason for these trips was not pleasant, the result was very good. I made new friends from different nationalities and cultures and I have the same wonderful feelings when I see them as when I see my old friends.

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Additionally, being part of any voluntary association means helping others, and this makes your heart big enough to love the whole world. In a few words, you become a better person because you realise that you are not the centre of the world and that everybody should be focused around your personal little problems.

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All these things helped me continue my life as well as I can and at the same time to be a useful member of society.

Going back to the point I started with, I conclude that health is a gift we should appreciate and celebrate every day. I realised it the hard way, being a patient with a rare chronic disease. The rest of you be blessed and enjoy it effortlessly.

“Health is a gift we should appreciate and celebrate every day.”

Despo Charalambous Demetriou Cyprus
My name is Despo and I am 40 years old. I am married and have a 6-year-old daughter, Nicoletta. I live in Nicosia, the capital of Cyprus.

I was diagnosed as having scleroderma in 2004. I work for my national rheumatic diseases association in my spare time. I realised that by helping other people we can help ourselves and also bring some happiness to ourselves. I love cooking for my friends and my family, and inviting friends over to my house gives me pleasure and joy.

I was informed about the Stene Prize competition through my national association. I was attracted by the topic because it has to do with my personal experience and I wanted to share my thoughts and feelings with people with similar conditions. I sent my application to my association for approval and when they chose my essay, I enjoyed the whole procedure. Writing was very easy as everything came from my heart.

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Despo and her daughter Nicoletta

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Despo and her daughter Nicoletta
A story about a wolf named Jack or a non-aggression treaty...
When I finish writing this essay, it suddenly occurs to me that I might not dare to send it in. I am shy. Do I even feel a little embarrassed?

This is a subject I’ve kept secret from most people for many years. The uncertainty and lack of trust in my own physical judgment and mental state have been in my life for so long that it still lurks in the background. Even though I now have the correct diagnosis.

"Is it possible to find another chair?", I ask tentatively. I don’t want to be difficult, but the angle of this hard, old chair makes my back pain approach the point of meltdown. The psychiatrist looks at me - analyzing. “We better examine your need for special treatment a little closer.” Then we do just that. I get no other chair. I do not stand up to walk around as I am afraid of what the psychiatrist might make of this.

I sit with the well-meaning psychiatrist and “sense myself.”

After several years of pain and medical examinations, the conclusion is: “life hurts.” Uncertainty riddles with me. Can I trust my own experience? Do I have terrible pain? Or is it something I am imagining to get attention? If it is, I really must be mentally ill. I am afraid, genuinely scared. Sensing and probing. Yes, there is grief; trauma even. Yes, I can feel them. But mostly I cry because of the violent and sharp pain. The fatigue. The daily pain in my heels that makes every step like walking on nails. Body and mind are linked and I am thrown wide open. Open to examination. The young rheumatologist is looking at me seriously. “We will send you to surgery, severe degenerative changes and Modic...” At this point I decide to stop seeing the psychiatrist.

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2 years later
I am at the rheumatology department assuming I will once more be told that I am physically completely healthy. An MRI has been forced through by a young rheumatologist who feels pity for our little family. “Do you have a little child?”, he asks with concern in his face. “But this has all taken too long,” he says in the knowledge that we must now get to the bottom of this. I am infinitely grateful for the look in his eyes.

We sit in the consulting room. The young rheumatologist is looking at me seriously. “We will send you to surgery, severe degenerative changes and Modic...” At this point I decide to stop seeing the psychiatrist.

5 years later
The fatigue and pain elsewhere in the body still cannot be explained. The years go by. I continue to exercise hard and wonder about all the unexplained relapses. This time I remain persistent! I do have pain! And the fatigue is not all in my mind. Oh yes, I am distressed and I do react emotionally, because no matter how hard I exercise, I feel bad. I feel powerless.

I must close down my successful life’s work. My own business, which I have fought for so many years to maintain, but now I must finally give it up. I must become a disability pensioner. Oh, yes. I react emotionally. I do need to see a psychologist. I am losing too much of my life, the fun and joy and freedom and content and meaning – it is not fair. I am only 40 years old. I live like a person of eighty years old... Experiencing social isolation; using my “spare time” on exercise, physiotherapy, rest, alternative therapy, fighting, fighting... you name it. Oh yes, I’m tired.

7 years later
Connective tissue disease? Enthesopathy?
Spondylarthropathy?
Inflammation? The questions pour out. “Does this mean that this and this are caused by the disease?” “Yes. It all fits,” she says. Her eyes show me that she understands - that I need to ask to understand. Worries are laid to rest. For example, it is not because of heart disease that I sometimes have difficulty breathing. It’s just the connective tissue disease. It is still unpleasant not being able to breathe properly, but I am not afraid anymore. Just short of breath.

The pieces are whirling around my head and finally fall into a clear pattern. I’ll be moving on. It will take time. But I do not have to search my soul or doubt or worry any more. I am just as neurotic as anybody else. But I am not crazy.

But I am not crazy. I hold on to this insistently. But I have doubts. After all it may all be in my mind. Fortunately, I meet a rheumatologist, I trust her. She doesn’t let me go and sees me for many years. And finally she gives me the answer.

“I am losing too much of my life, the fun and joy and freedom and content and meaning – it is not fair.”

My own doctor now tells me, that I shouldn’t have been referred to a psychiatrist. My physiotherapist changes my exercise program to fit my diagnosis. Now we understand why my body has been acting so strangely. Body and mind are still connected. But now I work the other way around. There is a disease and there is a reaction to it. It is now my job to look at it. “Because when it cannot be otherwise, it might as well be great,” a wise woman said to me once. I hope she will be right.

“Now we understand why my body has been acting so strangely.”
Annette Siegert
Germany

My name is Annette Siegert and I live in Berlin.

I am 35 years old and I have had symptoms of SLE (Systemic Lupus Erythematosus) since 1989, though I was only diagnosed in 1999. I love travelling, reading, singing, going to museums and learning about new things. I got interested and involved with the Stene Prize competition because it offers one of the rare opportunities for my disease to open a door to me and to become an asset and a precondition for doing something.

Below me lies the Mediterranean sparkling in the sunshine and the white skyline of Tel Aviv. I am proud of myself. This is no normal journey – this is my reward. My big fat reward for three and a half years of diarrhoea, nausea, skin rashes, abdominal pain, giddiness, unbearable fatigue and exhaustion - illness, only illness all the time.

The new treatment has made lots of things better – otherwise I wouldn’t be here. I walk through Jerusalem’s narrow alleys. I get so dizzy several times a day that I am afraid of falling over. Would anyone help me? Take me to hospital? Would they know there what lupus means?

I must hold out until I get back to Berlin. I simply carry on walking. Many people have asked me whether I wasn’t afraid of travelling to Israel. I am used to living in a crisis zone. My body is one.

“Would anyone help me? Take me to hospital? Would they know there what lupus means?”

The muezzin chants and my heart beats like mad. I am totally exhausted but I have not felt so alive for years. This constant need to look after myself.

Free of the fear of too much sun, too much cold, too much exertion, too little sleep, free of the fear of colds or infections.

Free of the fear of eating the wrong thing and getting diarrhoea.

Fear, fear, worries, worries. “What’s the matter with you then? You look so healthy.” This is what I was asked when I had to apply for more social benefits in addition to my pension because of my total incapacity to work.

I am tired of explaining what it means to have lupus. I would just love to run away once in a while without wondering whether my body can cope.

Back then, during my first attack when I spent 10 weeks in hospital, my kidneys almost failed and I could barely crawl to the lavatory, I decided I would fly to New York if ever I managed to return from this battlefield.

I got there. And I’ve got lots more places to travel to. I should like to travel to India, Albania, Alaska, along the Rhine, to Tokyo and Shanghai and live in Paris for a month.

Most sick people maintain they don’t want any sympathy; sympathy would be the worst. But for me, the worst is a lack of understanding.

“Most sick people maintain they don’t want any sympathy; sympathy would be the worst. But for me, the worst is a lack of understanding.”

But I never think further than a year ahead. I daren’t make plans for any further into the future. Next year I am travelling by rail to Kazakhstan. Landing in Tegel, if I fall over now I’ll be admitted into a Berlin hospital. It all turned out fine.

Translated by Verbalis GmbH
My own friend

One day you wake up and your life is different. In what way? In many ways, in the way you live, the way you think, the way you behave with other people.

Your universe has changed. Especially when you are in your teens as I was, this change happened in a dramatic way. Who did that?

It’s like an intruder in your life at the beginning, then a stranger and gradually he turns out to be an interesting visitor and maybe by the end he could be your friend. My own friend is called lupus and sometimes he reminds me of the well-known fairy tale where the wolf devours Little Red Riding Hood, but most of the time he’s a quiet dog.

In the beginning I had no idea what was happening. I’d never heard of this intruder. Only some scary rumours about what dangers he could bring to my life, or even that he might be contagious from people who obviously had known nothing themselves.

So if you don’t want to be haunted by unexplained fears and pitiful glances, you try to get to know him better and think why not make him your friend. It is true that when something is not widely known about or even worse, completely unknown to you, you are afraid. However, if you decide to light up darkness, it is no longer dark anymore and things become less scary. The same happened to me. I started getting to know my friend better, sensing him, trying to understand all the messages he was sending me and eavesdropping on my own body. I studied him literally and metaphorically. I looked for every single piece of information wherever I could and even invaded “my strange friend’s Facebook” to discover his club and find more “friends/colleagues” from there.

“Eventually the rare becomes familiar, you reconcile with him and move up to the next level. You have to explain everything to others and communicate your knowledge and personal experience. This is the most difficult task for me. Who is willing to listen to you without feeling prejudice, pity and fear? How do you tell them that it could happen to anyone? How do you persuade them that you are still a normal person, the same as you were before? How do you help them to know him and you end up being partners in the same quest.

“In the beginning I had no idea what was happening. I’d never heard of this intruder”

The doctors say he is rare and then they look at you with frowns and sceptical faces but they don’t tell you anymore, at least not in the beginning, because you can’t understand. They think, who are you to talk about medicine? In those moments they become demeaning, mean minded men trying to play God. The fact is they don’t know much either; they are like you, they are still exploring the “stranger”, and some of them have never met him before. You help them to know him and you end up being partners in the same quest.

Eventually the rare becomes familiar, you reconcile with him and move up to the next level. You have to explain everything to others and communicate your knowledge and personal experience. This is the most difficult task for me. Who is willing to listen to you without feeling prejudice, pity and fear? How do you tell them that it could happen to anyone? How do you persuade them that you are still a normal person, the same as you were before? How do you help them to know him and you end up being partners in the same quest.

Of course you have to recognise your problems; to face them and set them in the right context and convey to other people that although it is a rare problem but no less severe or less painful and you are no less one of life’s fighters. You are special and, like precious stones, need special care. You cannot be ignored because they have never heard of your condition. Apart from this, there is no excuse for overlooking a problem because it is not a common problem or not very well known. Besides, who can measure and qualify the pain or distress in life? No one, not even God.

“Who is willing to search for a possible solution when there are other more pressing problems and there is not even time or money for them?”

You are a normal person like everyone else in the world, with the same rights and the same needs, but you happen to face some health problems that others don’t. You cannot overcome them because they interfere with the normality of your life, but on the other hand you have no obligation to expose them to people’s curiosity. It’s a personal thing that you don’t need to describe to others in details. You just tell them what they need to know.
“What will you do now that you have been diagnosed with this illness?”

Csongor Arató
Hungary

I am Csongor Arató and I am 46 years old. I live in Pécs, Hungary. I am married and have four children and I like to go into the countryside with my wife and children by bike or on foot. I was diagnosed with SLE in 2003. I read about the Stene Prize on our national organisation’s website - I thought problems with sunshine won’t just affect me and I wanted to share my ideas about this question.

“What will you do now that you have been diagnosed with this illness?” asked my wife, when she found out that I must strictly avoid sunshine.

According to my doctor, sunlight starts an autoimmune response in my body, just as very dry twigs and fallen leaves can suddenly catch fire. I asked myself: “How am I going to take part in bicycle rides and in hikes in the woods and meadows?”

When the SLE illness first hit me, I could not expose myself to the sun without alarm. Only 5-10 minutes of sunlight on my skin left my face as red as a beetroot, or as we say in Hungary, as red as a hot Hungarian paprika. Where I live, in the southernmost region of Hungary, where on the South side of the Mecsek hills figs ripen in gardens, the summer is hot and the sun burns relentlessly. After I was diagnosed, I wondered if I would need to give up all outdoor activities.

Maybe there is a solution after all? I thought to myself. As I examined photographs of the Bedouin Arab people, I was struck by their clothing which covers their bodies from head to toe. In addition, to my knowledge, Hungarian peasants do the hardest summer outdoor work attired in hats and long-sleeved white shirts. Even during harvest time, these peasants do not take off their clothing. I thought that perhaps I could learn something from these two traditions, and asked myself if I could follow these examples.

Let me try, I decided.

I found that yes; one can row a boat in gloves, a long-sleeved shirt, and long trousers. It is of note, that even experienced rowers wear white shirts and wide-brimmed hats when in their boats on the water. On the right-hand side of the photograph, the man pictured learned to tie the style of headscarf he is wearing in Egypt, and ever since, he has dressed up like this to protect himself from Hungarian heat-waves.

With help from my family, I prepared an outfit based on the Mexican poncho, which shades my entire body. The poncho also protects me from the rain on my bicycle expeditions, and its design does not interfere with one’s cycling. At first, when I wore it on bike trips, the other cyclists looked at me with a little uncertainty. However, when I explained that under the cape my body is cooled, while their bodies are burned by the sun, they grew silent. It is a curious that in my experience the poncho does not warm my flesh, but instead provides a cooler body temperature. This costume - of course complete with a wide-brimmed hat - constitutes an appropriate protectant against the sun’s harmful rays.

Over the past decade, as ever more of the sun’s damaging UV rays penetrate to the Earth’s surface, even healthy people now need to think about protecting themselves from sunlight. I therefore hope that my experiences with sun protection will be of interest to both healthy and ill people, alike.

Translated by Ursula Pavlish
**Body versus Mind**

It’s still a bit dusky outside when the alarm clock goes off. With a stretched arm she presses the button to stop it.

For her body, it is too early to get out of bed. She is still enjoying the nice warm cocoon she has created under her duvet. Meanwhile her brain has slowly started to recall her ‘to-do list’ for today. Go to work, of course, and do not forget to make a reservation for a conference room for today’s meeting. Send a birthday card to her niece, and attend the gymnastics session. Measure the skirting boards and inform the shop, and, oh, she muthn’t forget to buy toilet paper.

It will be a pretty busy day and, last but not least, she will have to cycle from one end of town to the other.

With heavy legs she finally pushes the duvet away, gets out of bed and gets into the shower. Her morning routine has just begun. The hot water causes vivid red spots on her skin, but the warmth, as always, feels good. After drying herself off, she puts on her make-up in front of the steamed-up mirror. She also applies a cream to her upper lip. It seems to have darkened again. She has been doing this for the last six months, but it doesn’t seem to be making a difference... Why can’t she simply accept the spots?

According to the weather forecast in yesterday’s newspaper it is going to be a cold, sunny day. In her make-up bag she looks for her sunscreen, but the warmth, as she feels a pain in her chest.

The idea that her body cannot do what her mind wants frustrates her, but it forces her to make choices. It makes her do the things she really likes, the things that give her energy. It made her choose the studies she always wanted to do, and made her leave the stupid job and dull colleagues of last year. Her body will give its signals because it ‘knows’ what is right for her. Her body’s reaction is often better than the reasonings of her mind!

She goes into the kitchen, grinds some coffee beans and puts the percolator on the stove. After a few minutes, the room starts to fill with the lovely aroma of coffee. The moment she opens one of her kitchen cupboards to get something to eat, she feels she has no appetite at all. Or is she just being lazy? She could take her blinder and make a nice yoghurt shake with fresh fruit in it. But then she would have to peel a few oranges, and she doesn’t feel much like doing that. One of her fingers is still a bit swollen and it is painful to move.

All right, this morning she prefers to sit on the sofa and drink a cup of tea instead of standing outside when the temperature is only 10° Celsius outside.

She realises she has to make a move and starts to search for her handbag and shoes. While making some quick movements she feels a pain in her chest. She doesn’t feel very supple either. Suddenly her thoughts rush through her ‘mental agenda’ and she realises she has been very busy lately.

Recently, she received the keys to her new home. A lot of work had to be done to the place to make it fit to live in. For the past two months, she hasn’t had to go to work every day and, she and her home-help have painted the walls and ceilings. It seemed as if she wouldn’t get tired at all! The place wasn’t finished when she moved in, but she hoped to finish the work in her spare time. Up until now she hasn’t been very successful in doing so. Her new job might not involve such long hours, but it does take a lot of energy. After a hard day’s work she prefers to sit on the sofa and watch television, and enjoy a cup of tea instead of standing on a ladder and painting the French windows. How long will it take before her energy levels will be normal again?

**“How long will it take before her energy levels will be normal again?”**

Meanwhile she has had her housewarming party, and her friends didn’t mention the missing skirting boards, the sanded, but not yet painted window frames, and the funny wall that has to be painted with a primer before it can be finished. However, she would really like it to be finished. She wants everything to be in order, just as it is in everyone else’s(!) home.

She walks to her bike and puts her bag in the bicycle pannier. She feels the most September air on her cheeks and realises summer is over. Goodbye dry ar, hello moisture. Suddenly she feels a bit worried. Will this year bring another setback? It’s very likely after so many changes in such a short period of time. Autumn is always a risky period for her. Last year she reached rock bottom. For three weeks in a row her mind was all right, but her body didn’t function at all well. The idea that her body cannot do what her mind wants frustrates her, but it forces her to make choices. It makes her do the things she really likes, the things that give her energy.

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“**The idea that her body cannot do what her mind wants frustrates her, but it forces her to make choices.**”

Marijke Leek
The Netherlands

My name is Marijke and I am 31 years old.

I live in Utrecht, Holland and I have had SLE since 2000.

I am single, but I am deeply in love with my Cuban boyfriend.

In my free-time I like travelling, writing and painting pictures.

I was made aware of this writing contest [the Stene Prize] through the Rheumabond website and newsletter in the Netherlands. It is one of my first short stories and therefore I was, and am, very pleased to have received such a positive reaction.

I have had SLE since 2000.

My boyfriend and I on the street close to my home

Here I am at work in BSO

A self-portrait made in Barcelona
A rare, but no less severe, rheumatic disease

The cold breeze through the half open window gave me chills down my spine. “It’s a warm autumn day,” the doctor said.

His fingers touched my joints as I sat partly undressed on his green examination table. My mother sat on a wooden chair by the window and looked worried. We had been waiting for an answer for a long time. The doctor pointed at my clothes and asked me to put them back on. Still sitting in his office chair, he rolled over towards my mother. With a lowered voice he confirmed that I had juvenile arthritis. He didn’t notice that I had also heard what he said. I was still sitting on his table, frightened half to death and with tears streaming down my face. Even though I was only four years old I knew this was serious.

I got to travel a lot by plane after that. On every flight I made sure I got one of the special boxes of candy and toys they hand out to children on the plane. I sat happily in my seat with new crayons, a fresh orange juice and my favourite cookie in my lap. Eventually, I grew too old for the candy boxes, but the ongoing plane rides to the large hospital in Oslo continued. I hadn’t grown out of the juvenile arthritis as my doctor and I had both hoped I would.

A big part of my childhood took place in that hospital. I met other kids who knew what it was like to have a bad day. The people at the hospital were always so friendly and understanding. Unfortunately this was in harsh contrast to the experiences I had at school. The problem in elementary school was that neither the teachers nor the students understood how this affected me, nor how my aches could be so different from one day to the next. I was met with disbelief when I talked about my pain, and the other students would whisper about how lazy I was if I couldn’t attend gym class.

As I couldn’t take part in all the activities in the gym class, I was often asked to stay by myself in a small room where they kept the weights. Here I used to sit and daydream about being able to play soccer with the boys, about being a part of the dancing at the school ball, or about going to gymnastics competitions with my friend. I tried to join in, but my joints just hurt even more if I strained them. I still remember the continuous wish to fit in. But instead of fitting in I stood out. I still remember the continuous wish to fit in. But instead of fitting in I stood out.

I don’t go on plane rides very often anymore. I’ve been transferred to a different hospital, just a two hour bus ride from home. But with a full time art course, it’s a challenge to make time for the disease. Still, the monthly bus rides to and from the hospital, have been turned into productive time where I can read my lecture notes, sketch and plan my days. It takes a lot of organizing to make everything work.

My joints used to swell up, especially my hands and knees. This meant I had to have surgery and long stays in hospital, including rehabilitation. A few days after surgery, I would get my sketch book out of my suitcase. I would draw myself with my teddy bear swathed in white bandages in a fantasy world of nature. My right hand had been operated on, so during rehabilitation I trained my left hand to become the right one. I don’t go on plane rides very often anymore. I’ve been transferred to a different hospital, just a two hour bus ride from home. But with a full time art course, it’s a challenge to make time for the disease. Still, the monthly bus rides to and from the hospital, have been turned into productive time where I can read my lecture notes, sketch and plan my days. It takes a lot of organizing to make everything work.

Even as a little girl I was interested in drawing and spent hour after hour getting all the details right in my pictures. I sat by the kitchen table with my crayons because I couldn’t always go out and play with the other kids. I was separated from them, but I managed to turn this into something positive. It actually led to me being accepted by the Arts Academy of Norway.

When, as a child, you live with a hidden disease it is hard to be understood and taken seriously. When, as a child, you live with a hidden disease it is hard to be understood and taken seriously. When, as a child, you live with a hidden disease it is hard to be understood and taken seriously. When, as a child, you live with a hidden disease it is hard to be understood and taken seriously. When, as a child, you live with a hidden disease it is hard to be understood and taken seriously.

“I learned that there were many other kids who went through the same things, and fought the same battles as me.”

In my daily life as a grown up, the challenges are plentiful. The schools are not always well laid out, I’m not always able to make notes with my right hand during lectures, and sometimes I wake up exhausted. These challenges differ in strength and character, but I always find new ways to handle them: I take small breaks while working, I’ve learned to write and draw with both hands, and I’ve become good at doing homework in hospitals and on the bus. When you have a chronic disease it’s important to be creative and innovative in order to diminish the limitations the illness brings. For me life is all about opportunities.
My name is Violetta and I am married with three sons. I have SAPHO syndrome and I would like to tell you about one of the most difficult but at the same time happiest times in my fight against my disease.

I live in a small town in western Poland. For 15 years doctors tried to diagnose my disorder. It was an extremely tough time in my life. I remember never-ending visits to doctors and the excruciating pain that lived inside me, which I was unable to tame. It was like a beast of prey that was always hungry. It made my life really difficult. I remember a visit to my rheumatologist where I just stood and cried, unable to cope with the pain. Unfortunately, the doctor suggested I should be examined by a psychiatrist. The words I heard from the doctor, who was supposed to help me, hurt me a lot. However, I was ready to listen if it would only make the pain go away.

In 1999 I had my third son and that was the most difficult time for me. On the one hand, I told God that I did not want to live any longer, that I could not cope with the pain, but when I looked at my baby son, I wanted to fight. Elias was born prematurely. My doctor said, “If you can manage to breastfeed the baby until he is one year old, he will be healthy.” I believed her. I was not strong enough to hold him in my arms or to change him many times a day. When I looked at Elias’s smiling face I often cried because I couldn’t lift him up or hug him. The pain pierced through my entire body. I could not breathe freely. My husband and my older sons were there for me, I saw their fearful eyes, wondering what the matter was with me. My family and friends were also very helpful. I could always count on them. Despite the pain, I fed him until he was thirteen months old. It was hard, if it had not been for the children, I would probably have given up. I often asked God: “Lord, how long will I last?” As an answer I heard: “I share the experience of the ones I love.” At that time I underwent numerous examinations. In order to diagnose me all contagious diseases, MS and other disorders had to be ruled out. There was still no diagnosis. My case was difficult to treat. I did not agree to a stay in a hospital – I could not leave my son. On the other hand, I did not want to live, as the pain was killing me.

One day I met a wise doctor who did not say much, but what she said helped me a lot. “Either you leave your children for a while, or forever.” This is how I made the decision to go into the hospital. After a stay in the neurological ward I returned home without a diagnosis, and once again doctors recommended psychiatric treatment. I did not really care about the diagnosis; I just wanted the pain to disappear. The gynaecologist who supported me in breastfeeding the baby convinced me that I was strong and perfectly sane. He claimed that no mother suffering from depression would have fought so strongly to breastfeed her baby despite the terrible pain.

I had another visit in 2001. This time it took a rheumatologist and a dermatologist only a short time to diagnose my illness as psoriatic arthritis. From then on, my life and appropriate treatment began. I had days with less pain and I finally knew what was wrong with me.

In 2005, doctors at the Institute of Rheumatology made a further diagnosis – SAPHO syndrome. It had been nearly 20 years since first symptoms appeared. My life, my will to act and my dreams came back. I had always dreamed of having a driver’s license. I had already come to terms with the fact that the pain would not allow me to drive, that I would not be able to manage. Thanks to my treatment, I can now manage everything. I do not dream of driving a car anymore – I am a driver and I have passed the driving license exam.

One day I met a wise doctor who told me that the treatment did not take as many years. He has chosen me, but rather what I have chosen. I have never asked God why He has chosen me, but rather what the purpose of my burden is. I have thousands of never-ending ideas and dreams. I also have a hobby, crochet and embroidery, and I am able to enjoy it in 2005 I co-founded a regional Branch by the Association of People with Rheumatism and Their Friends. I want to help others, so they do not have to wait for many years to receive the right treatment. When living in a small town, access to specialists, proper treatment and information are much more difficult to obtain than in large cities. Now, together with my friends and with the help of specialist doctors, we undertake awareness campaigns and help other people.

My son’s diagnosis and treatment did not take as many years. He was diagnosed with Ankylosing Spondylitis at the Institute of Rheumatology. I know he is a brave boy. He has many beautiful dreams, just like I do. He is currently studying Tourism and Hotel Management at the Academy of Hotel Management and Catering Industry, he dreams about travelling and manages to fulfill these dreams. I hope that when he graduates, he will also have the energy to help others.

I live in Zbąszyń, which is a little town located in western Poland. My diagnosis was made in 2001SAPHO syndrome (synovitis, acne, pusuliosis, hyperostosis, osteitis) and my treatment started then. I am married and have three sons. My hobby is crochet and embroidery. As I was writing this essay I thought, writing this to motivate people to fight against pain. It’s worth people who lose hope in their fight. My dreams came back. I have never asked God why He has chosen me, but rather what the purpose of my burden is. Now I know, I am stronger.
The great challenge of managing a rare rheumatic disease

I am going to share a little bit of my story with you and tell you how, since I was a little kid, I have dealt with a rare rheumatic disease in children called Juvenile Arthritis!

“Juvenile Arthritis? What is that?” “Poor dear, so young and already in so much pain…”

“Juvenile Arthritis? You know you are going to suffer a lot all through your life, don’t you?”

“Oh dear, if you were you wouldn’t risk having children because they might also have diseases… Just look at how bad your arthritis is…” “Poor, poor girl…”

These were some of the things I heard as I was growing up which gradually increased my fears and decreased my self-esteem…

Juvenile Arthritis is one of a group of diseases that are not very well known and, as such, most people have very little knowledge of them. This can lead people to say inappropriate things, and sometimes this even applies to health professionals. This, I must say, was a bit of a shock to me!

When I was a child, it was normal to hear the neighbours asking my mother: “How is she? Is she doing better? So small and already like this. Poor girl…” They made me believe that I really was a “poor girl!”

Many times I asked myself: “Why are they saying this? ‘Poor girl’ me? Why is that?” I had so many unanswered questions inside me as I was growing up.

I did grow up, but it was not until I was about 20 years old that I truly realised what was happening to me. I gathered more in-depth information about my disease, started to put more questions to the doctors and was able to understand and face both other people and my disease better.

I have also learned how to protect myself from some of the absurd and intrusive comments other people have made throughout my life.

Once I went to the pharmacy to get some drugs to treat my arthritis. The pharmacist was very curious about my prescription and asked me if all those drugs were for me. When I answered him, he told me: “So young! You know you are still going to suffer a lot due to your arthritis, don’t you?” I just couldn’t believe that such a comment could come precisely from a health professional who should have understood better how harmful these words could be to patients. It would be easier to understand if he was someone without any knowledge about health, but coming from that guy…!

I didn’t know whether I should laugh or just shake my head and pretend I was the “poor girl” they thought I was. That was a role I was used to playing…

“Many times I asked myself: “Why are they saying this? ‘Poor girl’ me? Why is that?”

Happily I was strong enough to explain to the pharmacist what my disease was and how I could deal with it, the hopes and trust I had in medicine, and how I thought it could help me to change my future.

There have been many other remarks of this kind that I have had to listen to since I have had this disease in my life. Would you like me to give you another example?

I have always dream of being a mother, though many people in my family kept telling me: “Look here… be careful, if I were you I wouldn’t have kids because you could get worse or the child might have your disease, or some other condition… Better not to risk it!”

Whenever I heard these things, I used to say to myself, how can they say this to me? Dreams are the inspiration of life and I believe one should fight for one’s dreams! I believe I was born to be a mother too, and I’m going to fight for this dream of mine, no matter what! However, some doubts kept growing inside me…

One day, whilst I was waiting for my rheumatologist’s appointment at the clinic, I was talking to the nurse about this subject and asked her for her expert opinion on the matter. She said to me, “You know, if I was you I wouldn’t risk it because this disease is hereditary.” I thought this was absurd because, as far as I know, no one else in my family suffers from arthritis or anything similar.

Well, at the start of my rheumatologist’s appointment, I decided to solve these doubts of mine once and for all, and to ask the doctor the same question. He reassured me and told me that the risk was indeed very small. Juvenile Arthritis itself is not hereditary, but special care would be needed, both during and after pregnancy, in order to minimise any possible risks. He also said that sometimes people who have no special knowledge about these matters can speak out of turn. That helped me a lot! Anyway, I heard other rheumatologists’ opinions and they all agreed on this subject.

Once again I faced a health professional (in this case, a nurse) telling me incorrect things about my disease and my dreams for the future…! I once again had to make an effort to understand that the problem lies in the lack of knowledge about this relatively rare disease and this is something that definitely needs to change in the near future…!

“I had to make an effort to understand that the problem lies in the lack of knowledge about this relatively rare disease.”

As I told the pharmacist during the episode that I mentioned above, as well as taking good care of the diseases of our bodies and minds, it is also fundamentally important to live each day in the best way possible; to overcome our fears and to trust in the future, accepting whatever comes with open arms.

That’s what I do, day after day. That’s also what I think all of us should do, day after day! Be happy and “até sempre”…!”

Ana Paula Nunes
Portugal
My name is Ana Paula and I am 34 years old.

I am married and I live in Azeitão, Portugal. In my spare time I enjoy writing, dancing, reading and spending time with my pets or going out with friends. I was diagnosed with juvenile idiopathic arthritis when I was about 3 or 4 years old. One of my biggest passions is writing, so this competition was a big challenge for me. Besides, I think that it is important to raise awareness of rheumatic diseases (arthritis in particular) and that made me send in my contribution.

“It is fundamentally important to live each day in the best way possible; to overcome our fears and to trust in the future, accepting whatever comes with open arms.”

“People have very little knowledge of them. This can lead people to say inappropriate things, and sometimes this even applies to health professionals. This, I must say, was a bit of a shock to me!”

“Why are they saying this? ‘Poor girl’ me? Why is that?”

As my life goes on, I understand that I have two choices: either I decided to be a loser and be the “poor thing” that many thought I was, or to be a winner, fighting against my disease and all the nonsense spoken by many people around me.

“I had to make an effort to understand that the problem lies in the lack of knowledge about this relatively rare disease.”
My new daily life

You don’t need to worry, he said to me. With today’s treatments we can fix most things and when it comes to your fingers it’s an easy matter to fix - with a surgical procedure!

These three words - a surgical procedure - stayed with me a long time after I had left the doctor’s room. In addition, he had made a sketch on his notepad to show how these surgical procedures would be carried out. I sat there opposite him and broke out in a cold sweat. When he asked me whether there was anything I wanted to ask, I answered with a hasty no and left hurriedly. This is where my journey towards accepting the unwelcome guest that now lives in my body began. I must take the first step towards my new life; it will be a life with a somewhat altered daily routine, but I decided it would be a full life, not one filled with bitterness and anxiety.

I must take the first step towards my new life; it will be a life with a somewhat altered daily routine, but I decided it would be a full life, not one filled with bitterness and anxiety.

During the whole of this process I had enormous support from my family, friends and relatives. I had so much love and care from the people around me. This gave me a strength that I didn’t know I had. It gave me a desire to fight back and not wallow in self-pity. Some days life can still feel hard and unfair but I always pick myself up again. I think that despite a desire to fight on, you have to stop every now and then and allow yourself to think a few dark thoughts about the fate you have been dealt.

It’s a matter of finding happiness and an enjoyment of life even when everything feels heavy and hard. I try to enjoy the moments that give me happiness in life a little more; it makes my daily life lighter. It can be something like letting my family take care of me and make me a little bit more comfortable when they know I’m in pain or depressed.

I have so many of these happy moments in my life. They are not unique to me as a person with rheumatism, but I don’t lose courage and I battle on. Where does this strength come from? Have I always had it? Or is it something that my mind has built up after having gone through the setbacks?

I feel that I’ve come a long way in my efforts to live a daily life that is filled with happy things. Filling my life with happiness and laughter is very much my responsibility. Nowadays I think I live a life that gives me happiness. Of course I have days of pain and periods with hospital visits and tests, but despite miserable days I know that better days will follow. In both situations I try to maintain a cheerful and brave facade. It was, after all, my body that was ill, not my mind. But now I had it in black and white that after a diagnosis altered daily life.

The thing that helped me take that first step in this process was an item in a newspaper. I read that following diagnosis with a chronic illness, everybody experiences a process of grieving. Suddenly it seemed all right to feel bad emotionally. Previously I had tried to maintain a cheerful and brave facade. It was, after all, my body that was ill, not my mind. But now I had it in black and white that after a diagnosis like this you were allowed to feel bad psychologically... Now I felt ready to slowly but surely learn to live with my illness.

I must take the first step towards my new life; it will be a life with a somewhat altered daily routine, but I decided it would be a full life, not one filled with bitterness and anxiety.

I’m 35 years old and I was diagnosed with systemic lupus erythematosus when I was 24. I live in Malmö, in the south of Sweden with my husband and our son. I spend most of my spare time with my family, but I also enjoy reading and writing. Another hobby is gardening and we have a garden where I love to grow flowers and vegetables. The reason I wrote this essay is that I want you to know that is it possible to have a good life despite of your diagnosis. I read about this competition on the Reumatikerforbundet website.

During the whole of this process I had enormous support from my family, friends and relatives. I had so much love and care from the people around me. This gave me a strength that I didn’t know I had. It gave me a desire to fight back and not wallow in self-pity. Some days life can still feel hard and unfair but I always pick myself up again. I think that despite a desire to fight on, you have to stop every now and then and allow yourself to think a few dark thoughts about the fate you have been dealt.

Everyone experiences a process of grieving. Suddenly it seemed all right to feel bad emotionally. Previously I had tried to maintain a cheerful and brave facade. It was, after all, my body that was ill, not my mind. But now I had it in black and white that after a diagnosis this like you were allowed to feel bad psychologically... Now I felt ready to slowly but surely learn to live with my illness.

I feel that I’ve come a long way in my efforts to live a daily life that is filled with happy things. Filling my life with happiness and laughter is very much my responsibility. Nowadays I think I live a life that gives me happiness. Of course I have days of pain and periods with hospital visits and tests, but despite miserable days I know that better days will follow. In both situations I try to maintain a cheerful and brave facade. It was, after all, my body that was ill, not my mind. But now I had it in black and white that after a diagnosis altered daily life.

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Doris Brotschi-Lerch Switzerland

My name is Doris, I am 51 years old and I have limited systemic sclerosis with marked sicca syndrome, which was diagnosed in 1998. I am married, have three children and two grandchildren, and live in the village of Horriwil, in Switzerland. I like to take lots of exercise and enjoy the fun involved in being active. I also like doing handy-crafts.

My rheumatologist told me about this competition and encouraged me to participate. She thinks that I cope very positively with my disease, always looking on the bright side of life. Life is happening now - and you can still enjoy it to the full, even with a disease like mine. This is something I wanted to share with others.

Diagnosis: Limited systemic sclerosis with marked sicca syndrome

I had been suffering from inexplicable pains, fatigue and marked dryness of the mouth, eyes and especially the skin long before this diagnosis was made. I was sometimes almost at my wits’ end when scratching everywhere and applying ointment didn’t do any good. I used to take too many painkillers during this time! Then, after exhaustive blood tests, my doctor told me what was wrong with me. I was very happy to at last have a positive diagnosis, as I had sometimes felt as if I was just being a malingerer. It had been a long and difficult journey to this point!

I was then given a thorough examination at the hospital, Inselspital where this illness, its consequences and prospects were discussed with me in detail. It was rather a shock for me. I had never have imagined that I would develop an illness that I hadn’t even heard of! It was also very hard for my husband and our three children because this was the first time they encountered the reality that I might just die before them. The children were all teenagers. However, the fact that this hit my family so hard gave me unexpected strength; and I wanted to be strong for my children and my husband. After all I was, and still am needed. Apart from a few off days, I have actually managed to keep going very well right up to now! I decided to take a lot of exercise and not sit around at home waiting for the pains to come. We bought a dog. From that day on, I went out with the dog for at least two hours every day - even if I was in pain! I sometimes actually had the impression that I felt better after these walks.

The worst thing for me is when my eyes cannot bear light as a result of the dryness. When this happens I walk around outside with sunglasses on, even if I am in the shade. The first time it was really bad I only had 10% vision. I was almost at my wits’ end at that time. Thanks to my ‘Super Ophthalmologist’ and his encouragement I overcame this difficulty as well. It took almost a year before we got my eyes back to their previous level again. Unfortunately, I do keep having bad phases with my eyes. The last bad one was about a year ago and now I just have to accept that I will always only have about 70% vision.

“I think that those of us affected by this illness can live with it – you just have to accept it!”

Now I hope that for the time being my eyes will be OK. Even so, it takes a lot of discipline and medication to keep things on an even keel or so we hope. I’m afraid that my stomach has been through a lot as well. I can no longer manage without high doses of medication, but in spite of this, I keep having days with terrible stomach pains. When I am not feeling too well, at least I can always comfort myself that there are much worse illnesses - for me, cancer is much worse. I think that those of us affected by this illness can live with it – you just have to accept it! Of course, I realise that some of those affected have it much worse, because I meet some of them at the Inselspital on patient days. But I’m afraid that many of them have adapted their lives totally to the illness. But I tell myself, “I live for now and today.” I became a grandmother two years ago and have made up my mind to live to a ripe old age! I hope that I will far outlive the life expectancy for this illness.

Translated by Verbalis GmbH

Doris with her family
The challenge of coping with a rare rheumatic disease

The stranger in the shop regarded my gangrenous fingers with distaste. ‘Is it leprosy?’ she asked sharply.

‘No’, I said apologetically, but the woman had edged away, her face creased with disgust.

This is just one of the many challenges involved in having a rare rheumatic disease. Scleroderma is so uncommon that many people have never heard of it. Being a multisystem rheumatic disease, its effects are also often visible, so it can’t be hidden from view as many other illnesses can. And its manifestations can seem bizarre. Developing black gangrenous finger tips which drop off may well have got people burned for being witches in the Middle Ages. People were so different.

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The strangest and the one I thought I would never recover from was scleroderma in 1999. I was diagnosed with scleroderma in 1999. I am in a long-term relationship and I live in Glasgow, Scotland. I like reading literary fiction. I got to know about the Stene Prize contest through AFMA.

My name is Leyla and I am 45. I was diagnosed with scleroderma in 1999. I am in a long-term relationship and I live in Glasgow, Scotland. I like reading literary fiction. I got to know about the Stene Prize contest through AFMA.

Leyla Sanai
United Kingdom
My name is Leyla and I am 45. I was diagnosed with scleroderma in 1999. I am in a long-term relationship and I live in Glasgow, Scotland. I like reading literary fiction. I got to know about the Stene Prize contest through AFMA.

Leyla and her nieces

The challenges involved in living with scleroderma can be roughly divided into two groups. The first group consists of dealing with the disease. I have lost half my right (dominant) thumb and several fingertips. My fingers are curled into permanent flexion, and excoriating ulcers and calcinosis sit like jewels on my fingers, daring to be knocked. The ulcers become infected several times a year, necessitating long courses of oral or intra-venous antibiotics. Even lifting the smallest object is a challenge, and unscrewing any lid is impossible. Simple daily tasks like doing up buttons are beyond me. It’s so frustrating tumbling with my keys for ten minutes before being able to open my door; lunging at crumbs on the sofa multiple times before giving up and sweeping them onto the floor.

The muscles in my forearms have wasted away completely. The same process must also be taking place in my legs because walking tests as if I’m moving a ton of lead. Each step feels like I’m shifting heavy weights. But I have to force myself to take a 5 minute amble every day, because even a day without any walking makes my muscles stiffen and weaken to the point where limping to the bathroom is an effort.

Most of my large bowels have been removed in three laparotomies. The first was a sigmoid colectomy for a sigmoid volvulus, the second was for adhesions and internal haemiation of the small bowel, and the third was a subtotal colectomy for gangrene caused by a main artery of the bowel - the middle colic - becoming permanently blocked due to spasm and blood clot. Dealing with not having a large bowel - or at least, not a large, large bowel, ha ha, is one of the biggest problems in my life. Usually, in my dream, I’ve discovered with horror that I was meant to be working on a weekend and no one told me, so that I’m faced with the castigation and outrage of the people I’ve let down. Or, worse still, with their silent disapproval. When I woke up, it’s in a cold sweat and to mixed feelings - relief that inadvertently missing a day of work was not real, but intense sadness that I’ll never be able to do that work again.

Taking up to twenty medicines a day is also a challenge. The warping gives me nosebleeds and bruises, but without it, my white fingers don’t re-perfuse, infarcts occur and - so graphic - bits of fingertip fall off. The aspirin gave me gastritis and bruises, but without it, my white fingers don’t re-perfuse, infarcts occur and - so graphic - bits of fingertip fall off. The aspirin gave me gastritis and bruises, but without it, my white fingers don’t re-perfuse, infarcts occur and - so graphic - bits of fingertip fall off. The aspirin gave me gastritis and bruises, but without it, my white fingers don’t re-perfuse, infarcts occur and - so graphic - bits of fingertip fall off. The aspirin gave me gastritis and bruises, but without it, my white fingers don’t re-perfuse, infarcts occur and - so graphic - bits of fingertip fall off. The aspirin gave me gastritis and bruises, but without it, my white fingers don’t re-perfuse, infarcts occur and - so graphic - bits of fingertip fall off. The aspirin gave me gastritis and bruises, but without it, my white fingers don’t re-perfuse, infarcts occur and - so graphic - bits of fingertip fall off. The aspirin gave me gastritis and bruises, but without it, my white fingers don’t re-perfuse, infarcts occur and - so graphic - bits of fingertip fall off.

Breathlessness on exertion is another challenge. I used to go running every day when I was healthy. I still dream about running occasionally. But not as often as I dream about work. I had to take early retirement in 2002, and since then, I dream about my previous work at least twice a week. Usually, in my dream, I’ve discovered with horror that I was meant to be working on a weekend and no one told me, so that I’m faced with the castigation and outrage of the people I’ve let down. Or, worse still, with their silent disapproval. When I woke up, it’s in a cold sweat and to mixed feelings - relief that inadvertently missing a day of work was not real, but intense sadness that I’ll never be able to do that work again.

The other group of challenges consists of those involved with other people’s responses to my illness. The ignorance shown by the check-in girl above is one example, as is the woman who mused whether I had leprosy. I wish people would just ask instead of surmising. An elderly newsagent who I was paying for photocopies once snatched my money, giving me a filthy look, as if my thumbs stamp was down to heinous behaviour on my part. I’m touched by how lovely most people are, and by the support and love of my boyfriend and friends. I may not be physically active but I’m mentally as agile as I ever was, reading books, writing e-mails to my friends with my one functional finger, enjoying life to the full. Nowadays I have time to appreciate the beautiful colours of an autumn day; russets, golds and glorious oranges lighting up the trees. I have time to smile and chat to workers in the bank or library, whereas before, when I was fit and working, I was always in a frenetic, high-powered rush. Now, I also have the life experience to be able to empathise with people who have been through difficult times or disease. Sometimes it takes a catastrophe to make you a better person, and for that, I thank the catastrophe that is scleroderma.
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