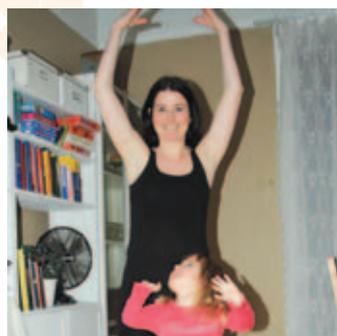




Lill Due



Practising with my daughter Juni



My family

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 "Folkeuniversitetet 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 the body, the stomach. It 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 and 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 day to day 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!



Lill the ballet dancer



Keeping fit



On the move in the gym



Teaching Juni to dance ballet

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 work out so your back doesn't stiffen up. Ankylosing spondylitis can cause the spine to fuse, ruining your joints. The worst case scenario is surgery and prosthetic implants.” They told me all this, but I didn't want to listen. I wanted to dance; to dance away all the pain and stiffness and the scary words. I kept on dancing on my good days, but on bad days I had to

stay in bed. What about my future - education, work and family? “Try to live as normal,” the doctors said. “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, was all I could think about. Up to that point I hadn't quite given up, but now...

“It's important to have physiotherapy and to exercise”, the doctors told me after I had my surgery. All I wanted to do was to stay in bed forever. “What's the use, I won't be able to dance anyway,” I thought to myself.

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. The pain decreased after a while. And even though it was painful to move around, with exercise and use of the muscles

that had been severed, I could put more and more pressure on my new hips. I could walk again! Before the surgery I couldn't walk, but now, after months of physiotherapy, I could “dance”.

“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”!