

2022 STENE PRIZE WINNER

NORA SOPHIA DUBILIER

Germany



I am Nora Sophia Dubilier and I am 28 years old. At 1.60m, I am described as a small person with a big personality. I was diagnosed with juvenile idiopathic arthritis when I was six years old and now have a secondary diagnosis of lupus.

I have a partner, live in Leipzig and have just finished my bachelor's degree in psychology. With this, I would like to work in the field of relationship and couple counselling, especially to help people with physical and mental impairments. I want to use my experience to help others. In principle, I always see the positive in situations.

In my spare time I am involved in sex education and education for relationship concepts (for example, organising a polyamory regulars' table) and take a fully inclusive approach. Before corona virus, I also did theatre.

I wanted to take part in the Edgar Stene Prize competition because I would like to make rheumatism more visible among young people. I have not had it easy with my diagnoses and my problems, and I would like to encourage people who have gone or have to go a similar way. I want to show that a diagnosis is not the end of the world. And of course I want to show every person, no matter what age, that there is always hope.

2022 STENE PRIZE - WINNING ESSAY

Lucky 13 - A young person with rheumatism looks to the future

First there was prednisolone. Then methotrexate. Etanercept. Adalimumab. Infliximab. Rituximab. Tocilizumab. Azathioprine. Leflunomide. Baricitinib. Tofacitinib. Another brand of etanercept. Im up to number 13 now: upadacitinib.

Thirteen combinations of letters. Thirteen mixtures of substances. Thirteen attempts to make part of me better. Thirteen drugs that have been at my side throughout my illness – rather like old friends. Thirteen basic medications in 22 years.

Thirteen: a number that sends shivers down some people's spines. Thirteen is supposed to be the devil's number and Friday the 13th is considered an unlucky day. In the tarot, the 13th card is "Death". In the USA, buildings rarely have a 13th floor and even the German Social Code misses out Section XIII.

Unlucky 13? Not for me.

For me, 13 means something else. A future.

For me, it's lucky 13.

Invisible

You don't hear much about young people with rheumatism. We are almost invisible in society. Nonetheless, it is important to be able to look forward to a hopeful future – especially when a diagnosis is made in childhood. When I was six, I didn't really understand what "juvenile idiopathic arthritis" meant, but I had a sense that it would affect my future. I wondered if I would have to grow up a bit more quickly than other children. Would I make it through school with a diagnosis like mine? How would my friends react? Would I still be able to join in all the games?

Years later, I still had just as many questions. Would I be able to take my final-year exams at school with rheumatism? Would I be able to move out and manage a home of my own? Would I be able to study? Would I have enough energy for a social life and a degree? Would I find a job despite my disabilities? What if I got ill too often? How would all this affect my relationships? Was I even attractive anyway with my problems? Could I have children? Was it a good idea for me to plan so far ahead?

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Many of the things I am struggling with are invisible. The traces of my disease that are visible on the surface are the least of my problems. What people don't see is the pain. The lack of sleep. The fatigue. The seemingly endless time I spend dealing with health issues. The frustration. The fear for the future. All of that is a far greater burden than deformed hands and feet.

Past and present

"Actually, I don't want my rheumatism to go away. Somehow, I am the way I am because of my rheumatism. I have no idea how I would have grown up without it! Maybe I would be totally different, and I wouldn't like myself at all."

When I said this aged eight to my parents, I left them speechless. But I was right. I am the way I am. My rheumatism belongs to me and I can no longer plan my life without it. I look at the future differently from the way healthy people do. It's not enough just to have confidence in myself and my abilities, the job market or my education - I also have to cope with this other part of myself. This means I have to deal with my past as well as my hopes for the future.

Looking back over 22 years of illness isn't easy to do. I have been lucky at times. The paediatrician in the small town where I lived made the right diagnosis straight away. Other people have lost years waiting. In 2001, there was a great deal of knowledge about treating rheumatism, but understanding of childhood and adolescent rheumatism was still somewhat patchy. Just a few years earlier, I would have had a much harder time of it - on the children's rheumatism ward, I met young people who were struggling with the consequences of medical ignorance. Only two years before my first attack of rheumatism, a young patient was prescribed complete rest for flare-ups. Her joints were splinted and immobilised. The result was that, in spite of good medication and improved therapies, she ended up in a wheelchair when she was only 10. I have been able to benefit from important innovations in treatment, and mobility and exercise therapy were already part of the picture back then.

Not everything has gone well for me of course. Twenty years after my diagnosis, young medical staff look at my hands in shock and tell me that deformities are not allowed to progress that far today. A mess was made of my feet and they have been permanently damaged. That may be true. But what good will complaining about it do? I feel better when I trust that the future will keep bringing solutions that are unimaginable at present.

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This is linked to the certainty that failed attempts at treatment are not the end of the road. It's like my lucky number 13: I could be unhappy about all the medicines that haven't worked. Instead, I prefer to be happy that I've already been able to try several drugs that weren't even on the market at that time!

It takes people to make it work

Medication alone is not the solution. It is only thanks to the many people who have helped me on my way that I have got to where I am today. When I am afraid of what the future will bring, or when treatments fail, I need a social support network that I can rely on. I need allies who stand by me and accept me as I am. I need friends to help me switch off and experience joy. I needed my parents, who taught me to stand up for myself, make my own decisions and tell my doctors what I was thinking and feeling. Unfortunately, I am used to having to argue with gods in white coats, used to not being taken seriously, used to feeling that I am not allowed to make my own decisions about myself and my body. This is also why I appreciate the fact that my current rheumatologist makes it so easy for me to participate in my own treatment. He asks for my opinion at every step of the way and accepts that I know my illness and my body best. Every single time my condition deteriorates, he takes it seriously and does what he can instead of putting extra obstacles in my way. I tried the last six basic medications with his support.

The present is my future

Rheumatism is part of me and it always will be. It is not an easy road to travel and it never will be. But every time my body lets me down, medicine has progressed a little bit further. Getting two hip replacements in your mid-20s? No problem! After less than a month, I was able to study for my exams again. Surgery on my hands? Even now, it makes me nervous, but I haven't given up hope that the methods will improve there too. Drug number 13 stops working? There are bound to be two new ones on the market soon.

Right now, lucky number 13 is my present and, hopefully, my future. Thanks to this and all the other medications, doctors and treatments, I have been able to finish school, pass my final high school exams and get a degree. I have left home, and I have successful relationships and a vibrant social life. I don't think I want children – but that's my decision and not because of my illness. It has taken 13 basic medications and 13 academic semesters to get me here. Thanks to my lucky number 13, I have been able to complete my bachelor's degree in psychology. Now it's time to share my lucky number with others. Thanks to that and my profession, I will soon be able to help those who have not yet found their lucky number.