

I have come a long way



Berlin Olympic Stadium, World Championships in Athletics 2009, one happy spectator

I had always been a perfectly healthy and very active child, playing competitive sports like table-tennis, soccer, and basketball. I also liked riding on horseback, and I took my bike whenever I wanted to get from A to B. But in my teenage years my life turned upside down because of my arrhythmia. I can't really say when it started, probably around the age of 13 or 14. At first I complained about tiredness and exhaustion, about palpitations, headaches and pressure in my head after exercising. In the beginning I didn't realize I had arrhythmia, though I sometimes thought that my heart rate was a bit fast. My mother took me to our family physician several times, often after having picked me up at school because the PE teacher had called and said that I was not doing well. Even though I was very symptomatic, the physician always stated that my problems were typical for a girl in adolescence – later I should learn that this is exactly what many teenage girls get to hear who do suffer from arrhythmia. He did say that my heart rate was a bit fast; he did say one could do a treadmill test or other ECGs, but he thought this wasn't necessary at all. My parents both trusted this doctor, and at that age I just didn't even think of seeing a different doctor on my own. So, that's why it took about four years to get a diagnosis. Within these four years, things gradually took a turn to the worse. I was so very tired, sometimes napped for hours after school. PE at school often was a nightmare, and I can't really say how I managed to keep up playing basketball at least twice a week – it was probably just will-power. One memory that has never faded is that even walking up ten stairs at home left me totally out of breath and extremely weak, sometimes I had to lie down on the floor afterwards. While my friends went out partying, I slept. Also, I started to become more aware of my heart rhythm, and often wondered whether it was normal to have a heart rate of 180bpm half an hour after having exercised or simply when I raised my hand at school to give an answer to the teacher's question.

Finally, shortly before my 17th birthday, I got to see an internal specialist. All those tests our family doctor had mentioned were done. It was found that my average heart rate was too fast, whenever I started to move around my heart rate was up to around 180bpm in a blink, and took a long time to slow back down; even at night I had episodes of tachycardia. My first diagnosis was “inappropriate sinus tachycardia”. I was referred to a cardiologist. Unfortunately, I ended up with yet another doctor who thought that I would probably outgrow the arrhythmia; he suggested waiting a couple of years. Fortunately, my internal specialist didn't agree at all and took action: he put me on a high dosage of beta-blockers, and then convinced my parents that I should see a specialist for heart rhythm disorders. So, half a year later, in spring 1999 I had my first appointment with Prof. Kuck in Hamburg. That's where I have been treated ever since.

Today, at the age of 28, I can say that the term “arrhythmia alliance” perfectly describes what I have inside my heart. Within the past ten years I have had various supraventricular tachycardias: I started out with a nearly permanent sinus-node re-entry tachycardia with an average heart rate of 120bpm at rest, followed by paroxysmal AV-nodal re-entry-tachycardia, ectopic atrial tachycardia, and atrial flutter. I have been treated with medications, underwent six ablation procedures, had a pacemaker implanted, and because of a very rare and serious complication I also had to undergo open-heart surgery. Currently, I'm on Amiodarone as well as Warfarin.

Despite all the struggles - and with the help of a great team of doctors in Hamburg - I was able to achieve my aims step by step: A-Levels, driver's licence, Bachelor of Arts in Political Science. Whenever possible I participated in extracurricular activities as for example travelling to the U.S. and the Netherlands with a group of students, volunteering at UN conferences in Geneva, attending summer school, doing several internships. At the moment, I'm completing my Master's Degree in Environmental Management while working part-time to finance my studies. Exercising and outdoors activities are high on my agenda, and whenever there is a big sports event in Berlin, you will find me somewhere in the audience.

It wouldn't be honest to say that I never get frustrated, sad or angry because I certainly do. From time to time I really sing the blues! But I guess that's normal, and as long as one manages to pick oneself up again, it's ok. For me, it helps to know firstly that I'm in the hands of the best EP one could possibly think of. He's always taking my complaints seriously; unlike those doctors I've had in the past. Secondly, it helps to know that there are others out there with similar stories and experiences with whom I can chat, e-mail, talk on the phone or even meet. It's a wonderful thing to be able to support each other. Family and friends are important, too, but those who really understand what you are talking about and going through are fellow patients. Last but not least, it helps to know that time is on my side. For example, when I compare my first pacer to the one I got last year, there have been many technological advances from which I benefit, especially with regards to the rate response when exercising. Also, new anti-arrhythmic medications are being investigated, and new ablation equipment and techniques are developed. I believe even for tough and complicated cases like mine, there will somehow be a long-term solution.

After all, my motto is: What doesn't kill me makes me stronger. Or as Ghandi said: When you believe in your strengths, you'll grow stronger every day.

Inga

Berlin