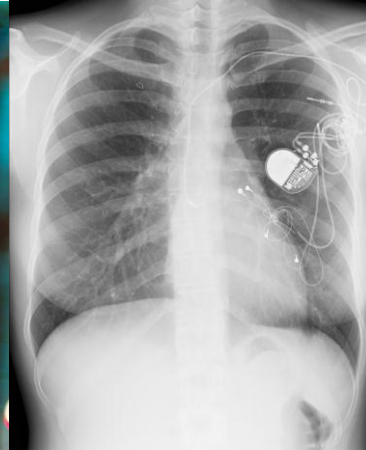




Festival of Lights, Berlin



My pacemaker

## I have come a long way

I had always been a perfectly healthy and very active child playing competitive sports like table-tennis, soccer, and basketball. I also loved to ride my Shetland pony, 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 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 EKGs, but he thought this wasn't necessary at all. Within the next 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 17<sup>th</sup> birthday, I got to see an internal specialist. All those tests our family doctor had mentioned were performed. 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”, later on it was called “permanent sinus node re-entry-tachycardia”. I was referred to a cardiologist. Unfortunately, I ended up with yet another doctor who thought that I would probably outgrow the arrhythmia, and therefore suggested to wait 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 a doctor in Hamburg. That’s where I have been treated ever since.

Today, at the age of 29, I can say that the term “arrhythmia” perfectly describes what I have inside my heart. I’m definitely not a poster child when it comes to arrhythmias and their treatment. Within the past eleven years I have had various supraventricular tachycardias: I started out with a permanent sinus-node re-entry tachycardia with an average heart rate of 120bpm at rest, followed by paroxysmal av-nodal re-entry-tachycardia, two ectopic atrial tachycardias, and atrial flutter. I have been treated with medications, underwent six ablation procedures, had six pacemaker surgeries, and because of a very rare and serious complication called “vena cava superior syndrome” I also had to undergo open-heart surgery. It is because of this complication that I cannot or should not have any more ablation procedures. So, currently I’m on Propafenone and Nebivolol to treat short episodes of SVT and AF and an accelerated idioventricular rhythm that leads to AV-dissociation (atria and ventricles not beating in sync) which I can’t tolerate well. My pacemaker is pacing my atriums 99% of the time, the ventricles 1%-10%, and when they test my heart rate without the pacer, it’s usually around 30bpm. I’m also on Coumadin to keep my reconstructed superior vena cava open.

I was on Amiodarone for a while which did a great job in controlling my arrhythmia, but damaged my lungs – fortunately, the damage was reversible. Within just eight months and with the very low dosage of around 100mg Amiodarone per day my diffusion capacity (very important lung function parameter when you take Amiodarone) decreased from 86% to 48%. So, if you are on Amiodarone, make sure your lung function is being tested every six to twelve months.

What might be interesting for some of you is that I have tried Dronedaron after I had to stop taking Amiodarone. Unfortunately, it caused by AV-node to slow down very much which resulted in my pacemaker having to pace my ventricles nearly 50% of the time as compared to 3% of the time without Dronedaron. Studies have shown that a lot of ventricular pacing can in the long-run – I’m only 29 so that’s very important - lead to heart failure and occurrence of AF, so that’s the reason why we decided to take me off Dronedaron, and try Propafenone instead.

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, as for example: Driver's licence, A-Levels, Bachelor of Arts in Political Science and a Master of Arts in Environmental Management. Whenever possible I participated in extracurricular activities, including 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, travelling to Norway, the U.S., and Crete etc. At the moment, I'm working as a research fellow and PhD student at the University of Potsdam, doing research about climate change in the Baltic Sea Region. 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. There are times when I panic because of a new rhythm or pacer problem; times when I feel sorry for myself or am really whiny; times when I look at my healthy friends and just wish to be as light-hearted (when it comes to health) as they are. 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 & cardio one could possibly think of. Both, my doctor in Hamburg and my Berlin cardio are 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, and with whom I can chat, e-mail, talk on the phone or even meet. I'm a very active member of three online support groups, trying to answer questions and sharing my experiences. 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 has been lots of technologic advance 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. So, I believe even for tough and complicated cases like mine, there will somehow be a long-term solution.

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

Inga

Berlin, Germany