



## ESC Patient Forum member Noémi de Stoutz

### Pregnancy in women with heart disease - safe for mom and baby?

I was born 63 years ago with a complex congenital heart disease: a “hole in the heart” and several parts missing. No operation was possible at that time. Despite the constant lack of oxygen, my body and brain managed to grow, and I was determined to become a doctor and a mother.

During medical school, my doubts about the possibility of going through a pregnancy increased. I was rather alone with this, my gynaecologist and cardiologist giving conflicting advice and data. What was my chance of surviving a pregnancy? Would my heart suffer damage? Would the baby survive? Would the baby be damaged by the lack of oxygen? Would it inherit the heart malformation? Would my health allow me to be a good enough mother for a long enough time? It was a long and painful process to come to my conclusion: I would be a doctor and enjoy other people's children!

In our Adult Congenital Heart Patients' Association, I met many women with malformed hearts. Some had children and many didn't, either because they decided against it or because it didn't work. I was a witness to many pregnancies, some of which were extremely difficult and dangerous. Miscarriages, highly premature babies, and children with dramatic health issues were common.

I belong to the first generation of congenital heart patients with a real chance of becoming adults. Nowadays, the majority survive to adulthood, but medicine is only just discovering the long-term outcomes of heart surgeries done decades ago. We, the patients with congenital heart disease, have tried things against medical advice, at our own risk. That's how medicine learns what works and what doesn't.

It took some courageous women to prove that pregnancy can be successful despite congenital heart disease. And that things also can go horribly wrong. It took many courageous women to get enough data for statistics about the risks. But the risk of each particular woman with congenital heart disease is never totally predictable.

Worldwide, girls get less medical attention than boys. In many countries and cultures, investment into childhood surgery for girls depends on their resulting marriageability - meaning their childbearing capacity. Still, there are now hundreds of thousands of young women out there with congenital heart disease. The risky pregnancies of these special heart patients require support from specialised cardiologists and gynaecologists working closely together. That level of care is accessible only in a few centres in some high-income countries. Everywhere, women and their babies go on dying in pregnancy or childbirth.

In a perfect world, the right level of care would be accessible to all women with congenital heart disease. There would be support for exhausted sick moms; for women who have miscarriages over and over again; for couples to cope with infertility.

I'm through with childbearing age. I'm still a woman. Old age with congenital heart disease is another new field for pioneering patients like me, and for their doctors who don't have data and evidence yet to guide their actions.