



European Heart Network
Fighting heart disease and stroke

CVS workshop on medicines and medical devices

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My journey



- Sudden weakness, dizziness, and rapid heartbeat **since adolescence**
- First cardiology visit **at 17**: dismissed as anxiety, prescribed tranquilizers
- **Symptoms worsened over 10 years**: loss of consciousness, prolonged arrhythmias
- Eventually **diagnosed and treated** for AV nodal reentrant tachycardia
- **Ongoing procedures**, including inconclusive electrophysiologic study in August 2025



... more than a decade later, some of my symptoms persist and I still have no definitive diagnosis nor treatment

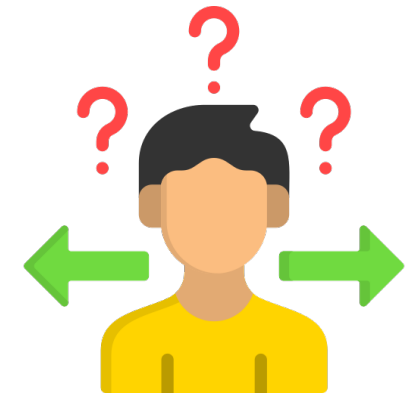
What I am left with



A decade-long
delay that cost
me precious
time



Multiple
procedures
during a crucial
stage of life and
career



Added stress,
uncertainty, and
lost
opportunities

Lessons learned



- ✓ **Listen without prejudice:** Safe care starts with listening to patients, no matter their age, and ensuring thorough investigations and timely diagnosis
- ✓ **Safety starts with thoughtful care:** Patient safety is not just about mitigating surgical risks but also means avoiding misdiagnosis, mistreatment, and years of delay.
- ✓ **Include early and meaningfully:** Patients should not only be involved in care decisions, but also in medicines and medical devices research, development, assessment and regulatory activities.
- ✓ **Provide patients real platforms:** civil society can amplify patient voices to decision-makers, being them researches, healthcare professionals or responsible for crucial policies

From individual experience to taking action



From my experience action

My job allowed me to seek for a second opinion, others might not have the same luxury

The first time I've worn a Holter I had to change battery every day. In the end, the device malfunctioned and failed to record my vitals

I am undergoing gender-affirming hormone therapy but no one could tell me how this might impact my symptoms

What this reveals

Patients are too often seen as passive recipients; dismissive attitude towards young people

Access to quality diagnosis, monitoring and treatment is uneven.

Only 27% of EU CVD trial participants are women; pregnancy, menopause, and hormonal impacts under-researched

EHN's call for



The Safe Hearts must strengthen patient partnership and age-responsiveness as a crucial part in HCP training

The Safe Hearts Plan should ensure equitable access to CV care and innovation.

The Safe Hearts Plan needs to embed gender-responsiveness and support gender-specific research