

PATIENT VOICE

Volume 2
ISSUE 2



SPECIAL POINTS OF INTEREST:

Voice For Change: Dayenne Zwaagman - From Patient to Advocate to Running a Foundation. Read her amazing story to see how she's overcome insurmountable obstacles and is affecting change in the Netherlands and around the world.

In This Issue:

- 2 From Patient Voice to Voice For Change
- 2 A Voice and a Heart For Research
- 2 V2 - Value Based Care with FHIR
- 2 Contributing Editor

My Adversity Leads to Hope for Others

By: Dayenne Zwaagman

If I was born ten or even five years sooner, I would not be alive.

I have had three open heart surgeries, I was flushed with liters of contrast liquid and bags of blood. I survived a cardiac arrest and a heart attack and spent too many hours of my life in a cath lab.

My name is Dayenne Zwaagman. Last month I turned 37.



Six weeks after mum brought me to this world, doctors finally came to her with a diagnosis.

It turned out I was born with a complex congenital heart disease. Its called complex because there were several extreme defects.

Life expectancy: unknown. The exact cause of all this: unknown. Most cases seem to occur by chance. Not easy (to solve).

I was born with a univentricular heart. Which basically means that my right ventricle was not developed. I was cyanotic, especially when mum was feeding me. The second problem: TGA, Transposition of the Great Arteries. The pulmonary artery & aorta arise from the incorrect ventricle.

The pulmonary artery & aorta arise from the incorrect ventricle.

The third defect: tricuspid atresia with pulmonary stenosis. The third defect: tricuspid atresia with pulmonary stenosis.

The first year of my life I underwent Blalock Taussig Shunt and Glenn procedure. I didn't know how a kid with this defects managed to stay alive and grew big enough for the first open heart surgery (Fontan) in 1988. The surgery went successfully. I survived and felt as normal a child could be.

Still Surviving...

Two weeks later I ended up in ICU because of a failing (heart)drainage system. On the way to the operation room, my heart flat lined in the elevator. It turned out I was having a cardiac tamponade. This is a condition were blood/fluid fill the space between the sac that encases the heart and the heart muscle. This places extreme pressure on the heart which prevents the ventricles from expending fully and keeps the heart from functioning properly. The congenital thoracic cardiac surgeon flew in a balloon pump which was never tried on a five year old before. This is a cardiac assist device/mechanical support for a heart in crisis.

My heart was functioning for less then 10 % capacity. Doctors told my parents that there was no hope for recovery. I somehow survived again! But the long-term functional impact on this disease is a lifelong challenging problem to treat. I took medication; did I need this until the day I die? What about my energy or concentration? Was I being able to go to school, or going on a holiday or doing sports?

Yes, I did it all! And yes, I could and still can move myself from A to B. I accepted a life with obstacles. I will never be the fast one and my illness can never be cured.



“
I started asking questions: What is that pill for? What does that read out mean? What do I need that for?”

PATIENT VOICE

Contributing Editor:
Cathleen McBumey
cmcbumey@visiontree.com

From Patient Voice to Voice For Change

Since 2013, I am living with only half a heart (I underwent another open heart surgery, TCPC: total cavopulmonary connection). From the moment I woke up in the ICU, I felt it was life-changing in many ways. But what I didn't know then was that it was also the moment that my role in patient involvement started.

I started asking questions: What is that pill for? What does that read-out mean? What do I need that for? For four days my heart rate told me

For four days my heart rate told me that the external pacemaker was not feeling comfortable for me. It made me sicker, please slow it down. Within a few minutes, I recovered.

Six weeks later I started cardiac rehab. Day by day, I got physically & mentally stronger. The standard cardiac rehab program is based on elderly people and did not challenge me sufficiently. So I asked for a taylor-made one. Which they gave me. Slowly my quality of life increased.

I know I might one day die. As far as I can tell I feel more alive then ever. I really don't know what gave my family and me hope during all this. All I can remember is that mum tells me that there will always be a tomorrow. And for now she is still right on that!

Two years ago I co-founded the charity Heart4Research. It's the first platform of patient representatives in the Netherlands that wants to build a bridge between patients with rare heart diseases and scientific researchers.

A Voice and a 'Heart For Research' Foundation

Just two months ago, we launched an app to this affect. We also finance research. And to raise the money, we facilitate sports events between the medical doctors, patients and their families. We don't do this only to improve treatment in the field of genetic and congenital heart disease in adults. But also because I believe that we need to work on improving the general quality of life of patients. That is why our board also provides educational lectures for medical students, nurses, cardiologists and other healthcare professionals.

Half a year ago Amsterdam UMC (the largest academic hospital in Amsterdam) hired me as the communication specialist at their Heart Center. It's my job to advice them on how to better prioritise the patient and their experience. I investigate how good we are doing and give lectures about the diversity of patient experiences, struggles, pains, misunderstandings and lots of emotion.

My illness and the way I am able to communicate about my experiences, something doctors

generally can't, brought me to the same hospital where I visit the medical team that takes care of me. Sometimes it still feels strange, when I sit next to my cardiologist in a meeting as his colleague. He and most of my colleagues are happy with me helping them and improving things. But still, there are also a few skeptics. Which is good. They keep me focused

I hope it will bring more humanity to the academic and medical world. I help professionals be more patient-centered. And I help patients understand their healthcare.

- DZ

V² Value Based Health Care on FHIR

The V2 Package with FHIR® APIs provides a plug-and-play solution for collecting and tracking specialty-specific patient outcomes measures and reporting tools for presenting practice-level outcomes for improved care and benchmarking, including the following key features:

- ePROs Library with Outcomes Templates & Alerts
- ePROs Access Anywhere Suite™ with Native Apps (iOS, Android)
- Rapid Reports Builder™ for Custom Queries & Population Health
- Predictive Analytics
- Global Benchmarking
- Shared Decision Making
- Quality & Cost Savings Reports
- Dashboards with Visualization Tools & Machine Learning