

# *“A Broken Heart is not the End... Just the Beginning of a New Adventure”*

The Heidi Dohse Story

[ A Presentation at the 60th MH National Convention - Dallas, TX ]

It is such an honor to be here and to have this opportunity to speak to all of you. This is my third Mended Hearts annual convention. When I attended my first Mended Hearts meeting / convention I was looking for answers and I wanted to meet people like me... Survivors of Heart disease. Today I want to share what I have learned.

A broken heart is not the end.... It is just the beginning of a different journey. This is a journey that many of you have traveled and because of the Mended Hearts organization, we are able to share our “lessons learned” with other heart patients.

Growing up I was fortunate to be involved in a variety of sports- starting with swimming, soccer then the high school track team. When I moved to Lake Tahoe I spent much of my time skiing and competed on the National Free Style ski team.

In my late teens I started windsurfing.... Eventually competing in World Cup Windsurfing events.

The thing is – during all my years of training.... I never could figure out how to take my pulse. I had no idea how all the kids in PE counted their heart beats and came up with a number like 72. The thing is it never occurred to me that I had a heart issue. I could always feel it racing and could see it pounding in my chest. It’s just that no one ever told me it was supposed to beat regularly.

At the age of 18 I was scheduled for knee surgery to clean up the mess I had made of them competing in all my sports.

During the surgery pre-op tests I finally had my first EKG.... As the paper strips were coming out of the machine I could see the nurses eyes get really big and she called the cardiologist in.

It was in that moment that my life changed. I went from being a healthy 18 year old athlete to a heart patient headed to the Coronary Care unit. I spent the next 30 days at University California San Francisco with doctors trying to diagnose my heart condition.

Turns out, the doctors had not seen anything like my arrhythmias at the time. They were amazed at how well I tolerated a heart rate of 270 BPM. The Doctors tried to control my arrhythmias with medication but nothing seemed to work. Finally they explained to me that they did not know how I managed to live as long as I had, and they were not sure how long I would be around.

So I did what any reasonable 18 year old would do...

I decided to live life to the fullest and move to Maui to windsurf.

The following year I was able to participate in an experimental procedure. To be one of the first humans to have an AV ablation. Basically the doctors would electrocute parts of my heart. Leaving me 100 % pacemaker dependent, for the rest of my life, at the age of 19.

This was a tough decision to make. I had no idea how I would feel. What if I could not be active or play sports anymore?

Of course as a 19 year old female, I wanted to know if what the pacemaker would look like sticking out of my chest. I had not ever met anyone with a pacemaker and had no idea what to expect.

And, of course, as a professional windsurfer, I had a swimsuit sponsor and I was not sure I would ever wear a swimsuit again and have people see my scar.

I chose to do the surgery because living and not taking toxic medications was a better choice for me. Yes, the first pacemaker I had did stick out of my chest like a pack of cigarettes.

Every now and then when I really think about it – I am still amazed that I run on batteries!

Through out all of my procedures, I have continued to train and compete in a variety of sports. Though because of how my pacemaker tracks my heart rate I had to change from fast “sprint” sports to longer endurance events.

Over the last 28 years I have had 6 pacemakers – each time the pacemakers improve and provide better more responsive heart beats. . Eventually though, I had to have my leads – the wires that go into my heart – replaced. Originally the doctors doing the procedure left the old leads in and just put in new wires and pacemaker on the other side of my chest.

A month later the scar opened up and it turns out an infection was brewing inside. So the doctors had to do emergency surgery to pull the old wires out. These leads had been in my heart muscle for over 20 years, so the pulling and twisting created a lot for scar tissue. Overtime the scar tissue that built up eventually blocked the blood flow around my heart.

For the first time I had to ask the question: Am I really a heart patient? Up until this time, I just figured I was a girl with a bad electrical system.

When I got the call from the doctor that to repair my vascular system they were going to have to saw open my chest and perform open heart surgery – I really thought he was joking. How do you prepare for open heart surgery? Well...

For me – I did not want to be a victim of heart disease. So instead I set a goal to achieve after surgery: I asked three friends to be on a relay team to ride the bike race in September. That would give me 5 months to train as each of us would have to ride a 50 mile leg for a total of 200 miles. I was being a tad optimistic because I had been diagnosed with heart failure due to the infection and had not ridden in a couple of years.

My other thought in preparing to have my sternum cut open and put back together with metal twisty ties, was to have pictures taken as a way of remembering what I used to look like before I had a scar down the middle. This could have also been my response to a mid-life crisis. Either way, it is amazing what a photographer can do with airbrushing!

The surgery lasted 13 hours and I ended up here in the ICU....

Day One:

Because healthcare is improving, the next day they already had me sitting up and moving around. It did not mean I liked it though.

Day Two:

At the end of day two I was feeling pretty good and looking forward to getting out of the ICU.

Day Three:

Until they started me on the blood thinners. I told the nurse that I felt like I was the “wrong” kind of sick. Something had changed.

I was swelling up and I could not even open my eyes.

Because I was strong, My body kept adapting and my vitals were ok, so the doctor on call said I was fine even though I knew something was really wrong.

Finally at 3:00 AM my body gave out and my vitals all crashed. They had to call a code blue and perform emergency surgery to drain the blood out of my chest.

Then they had to put 11 units of blood back in me using a special high speed transfusion machine. For the first time, no matter how much I wanted to live, I did not think there was enough of me left to make it. It turns out the doctors had not expected me to make it through that night.

Then I was back to the ICU.

Because of the fluid build up and blood clots that formed in my lung I then needed to have lung surgery 3 months later... which it turns out, hurts far more than open heart surgery.

This was a bit of a training set back on my path to achieving my post surgery biking goal. However knowing that I had three other people counting on me. I never thought of myself as recovering

from heart surgery. I was always thinking that I was training for the bike race. Though I had not expected to have to overcome this much trauma.

Ended up staying in the hospital much longer than planned so I had to start my training while still at UCSF. I began with creating a schedule for walking laps of the hospital floor. My husband now had a new roll as my support crew... he had to push my IV poles for me.

When I got out of the hospital I stayed at a hotel in San Francisco for a couple of weeks and was able to do my first 4 minute indoor bike ride on level 1. Before heart surgery, 4 minutes would not be worth putting my shoes on for. Now it was my gateway to getting my life back.

Then I worked my way up to getting back on my mountain bike to ride on trails away from cars. In case I passed out and fell over, I did not want to get hit.

Two months after leaving the hospital, I entered my first road bike event – though I felt kind of silly only doing the 10 mile route. It was about this time that I really wanted to understand what had happened to me and how open heart surgery would impact the rest of my life. That is when I found Mended Hearts and attended my first convention in 2010. I was inspired by the wonderful people that I met!

5 Months latter I reached my initial goal when I rode the final leg for our relay team and crossed the finish line at the LOTOJA Classic bike race.

On my 1 year anniversary of open heart surgery, I completed the 100 mile Tour de Palm Springs . Since it was only February and I had already completed my first 100 mile event... I decided to set my next goal. I would ride the 2011 LOTOJA Classic race solo. This was important to me because riding 206 miles in a single day from Logan, UT to the base of the Teton Mountains in Jackson Hole, WY, was about as far from being a sick heart patient as you can get.

In September 2011, 14 months after I got out of the hospital, I reached my goal.... And when I crossed the finish line I knew that I was still me and I had gotten my life back. Though you can't see it in the picture, there are tears rolling down my cheeks. I finished the race in a little over 13 hours.

So then the question was: what do I do with all that I have learned? Answer: Get involved to help others by sharing my story.

And finally, Ironheart Racing is a group of heart issue survivors that are living life to the extreme. These are athletes participating in endurance events to bring awareness and inspiration to others. These three organizations cover the spectrum of the heart patient experience.

I have found that there is a lack of information for athletes and active people dealing with heart issues. It some ways this has been frustrating for me, because what I want to understand is how to not hurt myself with too much exercise. So in order to provide a different patient perceptive and bring change, I have become involved with a few organizations. CardioSmart is the patient /

caregiver education channel for the American College of Cardiology and a partner to Mended Hearts.

And of course Mended Hearts, which all of you are familiar with, is a Patient Advocacy group that provides patients and their caregivers the opportunity to talk to other heart patients that have already dealt with the procedures or surgeries.

On my journey with heart issues and because my near death experiences, I have learned a couple of life lessons that I would like to share with you. The first is regarding fear. We often do not even attempt our goals because we are afraid, or anxious. So for perspective, I ask myself a couple of questions:

Will this situation I am afraid of or stressed about cause me bodily harm? Usually the answer is "no."

Alright, then will it kill me? That answer is usually "no" also.

That means, if we really break it down we are most afraid of a ding to our ego. The fear of what others will think of us if we fail. And that keeps us from reaching our goals.

And finally, I want to leave you with this thought: The greatest gift we are given is the ability to wake up every morning, put our feet on the floor, and determine what kind of person we want to be and what kind of life we want to live. It does not matter what happens and who you were yesterday, nor what might happen tomorrow. It is only today and what you choose to do with it. I hope that you all choose to live amazing lives....

Thank you!