



Living a full and meaningful life with congenital heart disease.

A JOURNEY OF THE HEART: Learning to Thrive, Not Just Survive, With Congenital Heart Disease

by Deborah L. Flaherty-Kizer

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A Journey of the Heart

*Learning to Thrive, Not Just Survive,
With Congenital Heart Disease*



Deborah L. Flaherty-Kizer

“She’ll never live.” Those were the first words my mother heard from her nurse after I was delivered. “Your daughter is blue, weighs only 3 pounds, and has some kind of heart defect. Don’t worry, you’ll have another.” This took place over fifty years ago. I’ve proved her wrong.

This is my story. It is my journey as an adult living with a congenital heart defect. It is a story of pain, perseverance, and triumph and of denial, acceptance, and victory over congenital heart disease (CHD). And I am not alone. The estimated number of adults living with CHD—one million—equals or exceeds the number of children living with CHD.¹

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Growing Up

I never really considered myself as having a “disease.” I knew I had something “wrong” with my heart, but I thought it wasn’t anything major. All I knew was that I was overweight and was a total failure at all things athletic. Of course, back in the late 50s and early 60s, many girls did not worry so much about being physically fit. It seemed more important to be a raving beauty (which I was not), thin (which I was not), and tanned (being Irish, I definitely was not). I did excel academically, however. I convinced myself that a girl did not need to be athletic, that I could go far on brains alone. Well, that was true to a point, but I eventually discovered just how much my physical health would limit me.

Year after year, I would go for my annual pediatric check-up, year after year the doctor commented on my “galloping” heart, year after year he would tell my mother I needed to lose weight. No one had diagnosed exactly what was wrong—we were told it was just a “murmur.” Medical technology was not that advanced back in those days.

As a teenager, I tried every fad diet there was, but without an exercise program, I was doomed to fail. It was a vicious cycle. I tired easily, so I figured I couldn’t exercise. I didn’t exercise, so I was always out of shape

and heavy. I never linked my tiredness with my “murmur.”

I never was under the care of a congenital heart specialist when I was young since the true extent of my heart disease was unknown. I was not treated “special,” nor did I receive extra attention from my parents. Typical of doctor-patient relationships of that time, my parents accepted what my pediatrician told them and did not seek another medical opinion. Not knowing there was a medical reason for my lack of athletic prowess led to some self-esteem issues, as I just couldn’t participate well in many childhood activities and felt like a failure. I dreaded gym class—I was always the last one picked for a team. I blamed myself. But at least I didn’t have parents who coddled me or refused to let me do anything. My childhood might have been very different if doctors had diagnosed my heart condition when I was young. At any rate, focusing on academics was my only respite and motivator.

From the time I was in elementary school, I dreamed of attending one of the service academies. My father, a graduate of the United States Naval Academy and an instructor pilot, perished in a plane crash when I was only six months old. I wanted to attend a service academy as a way of honoring him. Never mind that women were not yet admitted. When the women’s rights movement of the 60s opened up opportunities for women, I remember asking my mother if the

academies would admit women. She said they never would.

Fast forward to 1975, my freshman year at college. I could not contain my excitement when I heard that women would be considered for appointments to the academies. I knew this meant I would have to restart my college experience if I was accepted, but to me it was worth it.

I immediately went through the application process and just waited. And waited. I found out my status in a most unusual way. Early one evening, I received a phone call. It was a reporter from the *Boston Globe*. I was one of the first women to receive an appointment to the U.S. Naval Academy and he would be at my house in 30 minutes to interview me! I was speechless, the only sound being my pounding heart. My mother moved through that house faster than the Energizer Bunny® to get it into white-glove shape. The reporter soon arrived with a photographer in tow to capture my story. I felt like I was dancing on a cloud. The next morning, I saw my story and photo on the front page of *the Boston Globe's* Living Section.

I had sailed through the academic requirements; only the physical fitness test and physical exam remained. I knew the fitness test would be difficult, but it was harder than I thought. Candidates had to do a set number of pull-ups, push-ups, and crunches and run a mile. Almost twenty years of no exercise took its toll, and the first time I took the physical fitness test, I failed

miserably. My results weren't even close to what they needed to be. I was crushed. Determined to give it another try, I embarked on a physical fitness program designed to help me pass the "second chance" test. As a college student, I didn't have excess funds for gym memberships or trainers. I just used what I had available—extra gym classes that I could physically handle and the track. I even went so far as to use the shower bar for chin-ups. At first, I could barely do one, but within two months I was a chin-up champ, easily accomplishing seven!

The morning of the physical fitness test came around. I was nervous, but knew I had prepared myself to the best of my ability. I may never be a world-class athlete, but I felt I could conquer this mountain. And I did! I passed the test, and for the first time in my life, I felt physically strong. The only thing left was the mandatory physical exam.

It finally looked like my dream was coming true. My academy advisor called and gave me the news that I had been accepted pending the physical exam. In fact, he even said I had been assigned my roommate. He invited me to meet with him at his home, and we spent an entire afternoon discussing what life at the Naval Academy would be like. I couldn't have been happier. I remember him saying how thrilled he was for my appointment, and that it was about time women were admitted to the academies.

My ship soon sank. A few weeks later, my advisor called me, and I could sense he was upset. He told me that in spite of my passing the fitness test, in spite of my doctor saying I was physically able to attend the Academy, I had not passed the military physical. My acceptance had been rescinded because of my "condition." No specific diagnosis was mentioned, only that I should be seen by a congenital heart doctor because I had more than a murmur. I then realized that not being accepted into the Naval Academy was the least of my problems. I had no idea what I had wrong with me or how serious it was. My advisor assured me that if I wanted to fight the Academy's decision, he would be behind me 150 percent. I recognized that if I did, by the time I eventually entered the Academy I would have graduated college, so I cut my losses and moved on. I was devastated. I had never been discriminated against because of my illness; in fact, I didn't even know what condition I had! I was scared and frightened, and tried not to go to the "what if" place.

My quest to enter the academies led to my quest to uncover the nature of my heart ailment. I vowed then to do everything in my power to remain as healthy and fit as possible.



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