

# Living With CHD: The Patient's Perspective

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TOF with PA, absent PA and MAPCAs



seriously and within a year I had an electrophysiologist and an ICD. I also wish docs understood that CHD patients know and understand their bodies the best. When we say something is wrong, we're probably right. Patients need to understand that they are their best advocates. You can't be afraid to push for what you need. If an answer doesn't satisfy you, look for a second opinion. If a patient wants a second opinion is not necessarily a slight at the doctor or their care, we're simply being sure that what we need is what we get.

## "Me too!" The importance of community

ACHD community is HUGE. It wasn't until I attended the Beat Retreat Camp for the first time I realized the importance of connection in the CHD world. When you can have multiple conversations with different people and all respond "Me too" that is the moment you realize that you aren't alone in your battle. There is a unique and special bond among CHD patients. They're the only ones who "get it" and it's so important to have those relationships in your life. Because let's face it, few of us are surrounded by others that know exactly what we're thinking and feeling.

## Listening has been the greatest gift

The care I've received over the years has been second to none. I greatly appreciated when my cardiologist, Dr. Lucy Roche, sat down with me and told me I was palliative. It wasn't a rushed conversation and she made sure that I was okay and that she was leaving me in a position to get through the next stages of life. Lucy also never pushed me to get a double lung/heart transplant. She listened to my wishes and didn't once force her own agenda. That was the greatest gift she ever gave me.

## What I'd like ACHD team members to know

Having CHD can be a terrifying and overwhelming ordeal. The first time I went to Toronto General Hospital, I quickly realized that I was not at Sick Kids anymore and that "coddled" feeling you have as a child vanished. I think ACHD docs need to realize that transition can be terrifying. For me it was the first time someone took my complaint of palpitations



Jennifer, second from the left

