

Jamie is living with atrioventricular septal defect in ON. He was diagnosed at two months of age, when he was already in early heart failure and had open heart surgery at 6 months old. His mother, Vanessa, shares:

"I wish we had pushed earlier for more assessments given Jamie's other diagnoses - he should have had an echo much earlier than he did as the heart defect would have been found sooner and would have helped us identify the cause of his breathing issues sooner. When we were eventually taken on by the local hospital, they rushed him in for a consult and then immediately passed his file for discussion to Sick Kids as it was known that he would require surgery. Everything thereafter was set in motion quickly and done very well.

I think more needs to be done to inform families about the signs of heart failure. What to look for, how to monitor breathing, eating, etc. We felt like a lot of this was left to us to discover on our own and it pains me to look back and see videos of my child prior to his surgery clearly struggling but we just didn't know what to look for or how to help.

Having a CHD and having open heart surgery is one of the scariest things we've been through in life but it made us stronger. It grew our family closer. It taught us understanding and compassion. Despite the trials and tribulations, we're better people because of it and we're so thankful to have our Jamie still with us and fighting."

