What do we know about congenital heart disease and coronavirus?

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Congenital heart disease survivor Alex Cohen, in a photo he provided.

Like many 20-year-old college students, Alex Cohen is hunkered down and sequestered amid COVID-19 chaos. Some of his peers were frequenting their usual hangouts right up until many of them began shutting down, but not Cohen.

Once word of the coronavirus hit the news, it meant something different to him. Cohen was born with congenital heart disease and, like many with similar conditions, lives in fear of how the virus might affect him.

"It's a scary thing. People see me as a younger person, but I may be at risk—even though I don't know 100% how," Cohen said. "It's unknown, so I have to treat myself as if I'm at risk."

Cohen was born with pulmonary atresia, a condition in which the valve that releases blood from the heart to the lungs isn't properly formed. This pulmonary atresia is part of a syndrome called tetralogy of Fallot, a complicated condition comprised of four defects of the heart and its blood vessels.

COVID-19 can cause fever, cough and respiratory symptoms such as difficulty breathing. Cohen said because his conditions can affect his oxygen intake, he worries this will make him more vulnerable.

The challenge is right now there is no evidence to guide people living with congenital heart disease concerning their personal risks.

"The majority of the information available about this illness does not include information on patients with" congenital heart disease, said Dr. Anne Marie Valente, director of the Boston Adult Congenital Heart and Pulmonary Hypertension Program.

"When you live with congenital heart disease, the unknown risk is a real threat," Valente said. "Health care providers are working together to better understand the individualized risks and are counseling patients to be as prepared as possible and follow guidelines from the Centers for Disease Control and Prevention."

Currently, there is no data on congenital heart disease and coronavirus, but doctors in China observed in COVID-19 patients that many had coronary heart disease and heart failure. But those conditions are different from congenital heart disease, said Dr. Jamil Aboulhosn, director of the Ahmanson/UCLA Adult Congenital Heart Disease Center in Los Angeles.

However, he did say many patients had arrhythmias, or irregular heart rhythms, which are common for people with heart defects.

"We are keeping track of those patients and building a much-needed database," Aboulhosn said during a webinar organized by the Adult Congenital

Heart Association. "As of yet, we don't have any data for (congenital heart disease) patients."

Researchers are investigating whether angiotensin-converting enzyme (ACE) inhibitors, which widen blood vessels and are often prescribed for heart conditions, have a negative effect on COVID-19 patients.

On March 17, the American Heart Association, the Heart Failure Society of America and the American College of Cardiology jointly published a statement recommending patients continue medications already prescribed for conditions such as heart failure, high blood pressure and ischemic heart disease.

"Cardiovascular disease patients who are diagnosed with COVID-19 should be fully evaluated before adding or removing any treatments, and any changes to their treatment should be based on the latest scientific evidence and shared decision-making with their physician and health care team," the statement said.

Valente points out that general recommendations for people living with congenital heart disease appear no different from recommendations for the general population: wash hands for 20 seconds each time regularly; practice social distancing; cough and sneeze into a tissue and throw it away; and avoid touching your face.

Despite a lack of information about congenital heart disease and coronavirus, there are a handful of resources for patients. Michigan Medicine Congenital Heart Center has identified conditions it says may put people at higher risk for COVID-19 complications. They include pulmonary hypertension, heart transplant, unrepaired complex congenital heart disease and a single heart ventricle, which means one of the lower chambers of the heart hasn't developed, reducing the amount of oxygenated blood to the body.

Valente said it is important for people with congenital heart disease to remember that this time of unrest and uncertainty is not permanent.

"We all need to adjust our activities for this period of time, to stay strong and in greatest overall health, to guard ourselves, and to respect each other by protective distancing," Valente said.

For Cohen, he is walking an emotional tightrope—trying to find the happy medium between caution and panic.

"For now, I'm just planning to stay in and I'm being careful," he said. "If I get sick, it could really hurt me or it could do nothing. I'm trying not to get too freaked out."