BACKGROUND: Congenital heart disease is a defect present at birth. The defects can involve the walls of the heart, the valves of the heart, and the arteries and veins near the heart. They can disrupt the normal flow of blood where it slows down, goes in the wrong direction or to the wrong place, or is completely blocked. Symptoms include a bluish tint to the skin, fingernails, and lips, fast breathing, poor weight gain, lung infections, and being unable to exercise. Children and infants in the past have passed away from congenital heart disease, but with advances in diagnoses and treatment, the babies live well into adulthood. However, adults affected as children can still have issues arise as symptoms. (Source: https://www.mayoclinic.org/diseases-conditions/adult-congenital-heart-disease/symptoms-causes/syc-20355456)

DIAGNOSIS: Tests should be run, including the electrocardiogram (ECG,) which measures the pace and amount of electrical activity in the heart, an echocardiogram, which measures through sound waves, an exercise stress test, which is conducted by running on a treadmill, a cardiac catheterization, which checks blood flow, a CT scan, which is an x-ray, or a MRI, which uses magnetic field and radio waves to measure the heart. (Source: https://www.mayoclinic.org/diseases-conditions/adult-congenital-heart-disease/diagnosis-treatment/drc-20355461)

TRANSITION OF CARE: Doctors at Mount Sinai in New York have adopted a Transition of Care for patients of Congenital Heart Disease. Once patients outgrow their pediatricians, they lose contact with medical professionals concerning their defect unless an issue arises, so there is no transition to a doctor that treats adults. Starting at age 15, teens will be able to meet with an adult cardiologist while continuing their time with a pediatrician. Through several visits, the teen patient will discover their condition and develop an individualized plan to enable them to take control of their own health care decisions as they become an adult. (Source: https://www.mountsinai.org/locations/childrens-heart/services/adult-congenital)

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If this story or any other Ivanhoe story has impacted your life or prompted you or someone you know to seek or change treatments, please let us know by contacting Marjorie Bekaert Thomas at mthomas@ivanhoe.com