

Chicago-area hospitals collaborate to form first network for adults with congenital heart disease

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Seven major academic medical centers and teaching hospitals in the Chicago area have joined together to form the Chicago Adult Congenital Heart Network (CATCH), which is the first patient-centered, inter-institutional network in Chicago established to ensure all adults with congenital heart disease in the area receive appropriate follow-up care.

The CATCH group will hold its first meeting on Saturday, October 20, 2012, from 9 a.m. until 3:30 p.m., at the W Chicago Lakeshore, 644 North Lake Shore Drive.

CATCH members include nationally renowned pediatric and adult cardiologists and cardiac surgeons from Rush University Medical Center, University of Chicago Medicine, Lurie Children's Hospital, Northwestern Memorial University Feinberg School of Medicine, Loyola University Health System, Advocate Lutheran General Hospital and Advocate Christ Medical Center.

"Babies born with serious congenital heart defects are living into adulthood thanks to surgical repairs and other interventions," said Dr. Damien Kenny, secretary of the CATCH executive committee and associate director of the hybrid catheterization suites at Rush University Medical Center. "But after pediatric care ends, these patients become adults lacking adequate follow-up care."

"Adults with [congenital heart defects](#) are a fairly vulnerable population," said Dr. Joel Hardin, president of the CATCH executive committee and director of pediatric cardiology at Loyola University Health System. "This is an underserved field, and for the first time, there are more adults with [congenital heart disease](#) than children. We need to ensure these adults in the Chicago area receive adequate follow-up care."

Survivors of congenital and structural heart defects have a greater risk than other people of developing additional heart problems because of changing blood flow patterns in the heart. Long-term problems include rhythm disturbances, valve problems, heart failure, endocarditis, and stroke.

"When you have a heart with abnormal anatomy you will have abnormal stresses and strains on the corrected heart, and that will add additional challenges that can threaten the longevity of the corrections," said Dr Peter Varga, CATCH executive member and director of the center for adults with congenital [heart disease](#) at University of Chicago Medical Center.

Frequently, patients present to the centers when they start to develop problems, such as fatigue, exercise intolerance, chest pain, and shortness of breath or palpitations. Clinicians at specialized congenital and structural heart centers obtain past medical records and work up patients to determine their current condition, evaluate blood flow through the heart and identify structures created or remnants of the original congenital condition. The team may recommend additional surgeries, interventional procedures or medical management.

Physicians, nurses and advanced practice nurses involved in the care of patients with adult congenital heart disease as well as public health officers and agencies and patients and patient support groups attending the first CATCH meeting will hear from guest speakers such as Amy

Verstappen, the CEO of the Adult Congenital Heart Association, Dr. Gary Webb, director of the Cincinnati adolescent and adult congenital heart program and Dr. Michael Earing, the director of the congenital heart disease program at Children's Hospital of Wisconsin.

Attendees will learn about the important factors which affect the long-term outcomes and quality of life in adults with congenital heart disease, learn how to utilize pre-existing national guidelines for the management of adult patients with congenital heart disease, how to collaborate with Chicago's cardiac specialists to evaluate and treat this special patient population including the management of pregnant adult congenital heart disease patients and more.

CATCH was formed in order to create awareness of the need for appropriate follow-up of adults with congenital heart disease, who need to be followed on a regular basis by someone trained in adult congenital heart disease.

About one million American adults and 800,000 children live with congenital heart diseases, according to the Adult Congenital Heart Association.

Results from a past indicate that 63 percent of the 158 patients seeking care at an adult congenital heart clinic from 2002 to 2005 had left pediatric care two or more years before seeking adult cardiac follow up. The median duration was 10 years, and the most common reason for not seeking care was the patients were told they did not need follow up, which clinicians now know is not the case.

"We need to make sure adults who had a congenital heart defect corrected at an early age need to follow up and are at risk for things we now know about," said Kenny. "Adults with congenital heart disease are more prone to arrhythmias and a variety of complications depending on

their defect."

"CATCH exists in order to help follow practice guidelines for adults with congenital heart disease so that these patients can live into adulthood and have a full life," said Dr. Roger A de Freitas, CATCH member and director of adult congenital heart disease at the Robert and Ann Lurie Children's Hospital.

Provided by Rush University Medical Center

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