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Patched but not cured

Adults with heart defects ignore risks or struggle to find age-appropriate care

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In the 1950s, 90 percent of babies with congenital heart defects didn't live for more than a year.

As medical technology evolved, the trend reversed itself: Now more than 90 percent of such babies survive into adulthood.

That's the good news.

Now for the bad news: Adults with congenital heart defects, or CHDs, have trouble getting the care they need for their special hearts.

Now for some even worse news: Many of those adults don't realize they need specialized health care.

That's something Dr. Michael Earing and the Adult Congenital Heart Associa-

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tion are trying to change.

Amy Verstappen, ACHA's president, is leading an education and awareness campaign for patients and doctors. The campaign encourages adults with the condition to carry a "health passport," learn about their heart conditions, be able to communicate with their doctors and find the care they need.

Earing is a Medical College of Wiscon-

sin faculty physician practicing at Froedtert Hospital and Children's Hospital of Wisconsin. He also is the director of the Herma Heart Center Adult Congenital Heart Disease Clinic at Children's Hospital.

He's one of a handful of adult congenital heart disease specialists in the country and the only one in Wisconsin with formal training. He, too, has become an advocate for their care.

Common and misunderstood

Here's the problem ACHA is facing: Congenital heart defects are the most common group of birth defects, occurring in about 9 out of 1,000 births.

Now, for the first time in history, more

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adults than children live with heart defects. The number of those adults is expected to grow 5 percent every year.

"It's a funnel shaped group," Verstappen said. "And there's a large population out there that believes they were cured as children. They were told, 'Go home, you're fixed.'"

Alyssa Berg agreed.

Berg, 33, of Janesville lives with CHD and reaches out to other patients.

"A lot of parents were under the assumption that their child was fixed," Berg said. "And what they might not understand is that they're at a higher risk for heart disease because of anatomy and because of scar tissues."

Verstappen said she can't count the number of times when she's been on the phone with a person who makes a donation and says, "Oh, I had that when I was little." When Verstappen asks about the person's current health care, she often gets one of two responses: "I'm cured," or "I don't have chest pains."

Troubled but ignored

About 50 percent of adults with heart defects need specialized care, and all of them need periodic heart checks with doctors who understand their conditions.

"There are more than 35 ways your heart can be shaped funny," Verstappen explained. "I like to compare it to a house with a lay-

out problem. You can have hallways that are too narrow or doorways that are in wrong or weird wiring."

Replacement parts can wear out, patched hearts can weaken—plenty can happen to hearts with mended defects, Verstappen said.

And here's another problem: The signs and symptoms of trouble can be subtle. Instead of searing chest pain, they might get swollen ankles or simply feel more tired than usual.

"The problem is that patients who have had heart disease all their lives restrict themselves in what they do anyway," Earing said. "Often they don't have a lot of extra symptoms."

Once the symptoms become noticeable, it's harder to make a fix. Ironically, in order to have open-heart surgery, you can't be too sick.

Frustrated and mislabeled

Finding care isn't easy.

Verstappen recounted her own story. A well-educated woman, she often found herself in the position of having to explain her heart defect to doctors. For a while, cardiologists were convinced she needed a heart transplant because of the size of her heart. But her heart appeared larger because of the way it was shaped.

Adults with heart defects recount stories of being labeled "depressed," "anxious," "in denial" or simply hypochondriacs. One person was told the pain in her chest and abdomen was gas.

"You can't expect that anybody

in the medical system will know about it," Verstappen said, without bitterness.

Berg echoed that sentiment.

"It's not their fault," Berg said. "It's because they don't have the training."

It's important to keep in mind that doctors are dealing with the first wave of such adults.

"It's a young field," Earing said. "The first open-heart surgery was done in 1955, and the patients got amazingly better."

Which led doctors to pronounce them "fixed."

The Herma Heart Center is a big step forward for patients, but it isn't well known outside of the Milwaukee and Green Bay areas.

Along with providing specialists, Herma Heart has social workers who talk to patients about the emotional challenges of their disease.

"It's more than having a doctor, it's having a team," Earing said.

Worried and involved

Berg had her first operation when she was 4 weeks old. She had no pulmonary artery—that's the artery that transports oxygenated blood from the heart to the lungs.

Since that time, she's had six more surgeries to replace the artificial conduit that runs from her heart to her lungs and to put in a pacemaker.

"I always joke that I have to go in every 33,000 miles," Berg said.

As an adult, Berg saw a pediatric cardiologist at University

Hospital in Madison until she found a Mayo Clinic doctor who specializes in her condition.

"You're born with a childhood disease, but now you have an adult's anatomy," Berg said ruefully.

Although Berg has found the care she needs, she struggles with the emotional toll.

"I have 101 emotions when I go to the doctor," Berg said and started to cry. "You know when you go into surgery, you might not ever see your loved ones again."

Berg is married and is a stepmother. And despite her heart defect, she was able to have a child.

"You're faced with your mortality every day," Berg said. "You know the surgery is what saved your life, but you know it's what could kill you."

Berg and others are participating in a lobby day Tuesday, Feb. 13, asking their elected representatives for funding for research at the National Heart Lung and Blood Institute, which is part of the National Institutes of Health.

They're also hoping for a national heart registry that would provide an electronic list into which emergency rooms and hospitals could tap for patient information.

Berg carries a "health passport," but she worries about what would happen if it was lost.

She also wants to reach others who don't even know they need care.

"There just needs to be more awareness," Berg said.