

# Family-Centered Care: The “Heart” of addressing genetic heart disease

By Dr. Benjamin M. Helm

Reading his recent cholesterol test results, the healthy 31-year-old gentleman worries about his own risk of heart disease, recalling memories of relatives with heart attacks, stents, and bypass surgeries. He calls his closest cousin, “How old were you when your dad died of that heart attack?” He reflects on his toddler, who just learned to walk recently, motivated to keep himself healthy for her. “Um, I don’t know exactly, but I was maybe 8 or 9 when it happened,” the cousin says.

Our 31-year-old receives a message from his family physician, detailing his LDL cholesterol being “230”—normally, it should be below 100. The 230 is a shocking number. “It’s probably genetic,” the doctor says.

These anecdotes are common in our cardiovascular genetics work, with countless people discussing themes reiterated by their doctors and relatives. “It runs in our family,” “It’s likely genetic,” and well-intentioned

quips to lessen self-blame: “Genetics are unfair, man.”

As the Family Heart Foundation has discussed, “Runs in the family” is an unacceptable final diagnosis; for most people it is only the start. And this start requires a perceptual shift—one that does not see individuals as seemingly uncommon “n-of-1” cases to be simply treated—but one that holistically views them as microcosms of a larger family picture, one in which we have a duty to address risk in multiple, potentially numerous, people. Addressing this requires both a clinical perspective—diagnosing and treating individuals—and a public health perspective. The public health perspective addresses collections of people—like families—and seeks opportunities for disease-prevention and risk-reduction in those at risk of heart disease.

This work takes coordinated effort and a firm conviction that centers care for both the individual and their family. As a genetic counselor and epidemiologist in the Cardiovascular Genetics program at Indiana University Health, I am fortunate to work with teams who share this conviction in our clinical work, research, and community outreach.

After all, genetic heart diseases are agnostic to one’s age, geographic location, or social situation. Whether it is long QT syndrome, hypertrophic cardiomyopathy, familial aortic aneurysms/dissections, or familial hypercholesterolemia—like our 31-year-old gentleman might have—these familial disorders often affect families across the lifespan.

This “lifespan perspective” means that we must develop care models

that span pediatric and adult medicine, including different medical specialists, and even cardiology subspecialists, each of whom may have varying degrees of focus on the family. We also develop relationships with entire families, sometimes over the long-term, and provide outreach for identifying and addressing genetic risks of heart disease.

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Helm



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# From allergy symptoms to life support: A story of survival and advanced care



The Smith family is enjoying time together because they took unexplained symptoms seriously and sought medical help. Photos provided by Community Health Network.

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What he first thought were allergies nearly cost Michael Smith his life. In April of 2025, Smith developed a persistent cough that continued to grow worse. The 46-year-old BMO bank branch manager from Greenwood put off going to the doctor. “As many men do,” he says.

His wife, Clara Daoud-Smith, and his work team urged him to get help. After weeks of no improvement, Smith took their advice and was diagnosed and treated for bronchitis, but he still did not get better.

Smith says he was not eating much but started gaining weight, which alarmed him. He could not stop coughing. He felt tired all the time and had no energy. In June, Clara noticed something else alarming: his nose was turning blue. On Friday June 13, Smith arrived at work and saw that his arm was turning blue, too. He called Clara, who made the decision to take him immediately to the Emergency Department at Community Hospital South.

Smith has kept a steady weight of under 180 pounds for most of his married life. When he got to the ER, he weighed 234 pounds. His care team determined this was water weight from organ failure. Smith says his left lung was 80% full of fluid. He was struggling to breathe and, suddenly, his heart stopped.

The Community ER team worked to save Smith's life. Clara says it took 20 minutes to resuscitate her husband.

Once stabilized, Smith needed advanced care to survive. He was transferred to Community Heart and Vascular Hospital under the care of cardiothoracic surgeon Dr. John Storey. With potential damage to his lungs, heart, kidneys, and even his brain, the team turned to ECMO—Extracorporeal Membrane Oxygenation.

ECMO is a specialized life-support therapy that temporarily takes over the function of the lungs—and even the heart—using an artificial lung to oxygenate blood outside the body. This gives the organs time to rest and heal.

According to Dr. Storey, it is uncommon to see a man of Smith's age, who had been fit and healthy up until this point, in the hospital on life support. But the patient's regimen of exercise and eating right made an enormous difference in his recovery.

Smith was unconscious from Friday until Wednesday. When he woke up, he learned he had missed the celebration of life service for his best friend's wife. He was devastated and said his heart went into atrial fibrillation. His care team used cardioversion, electrical shocks, to reset his heart rhythm.

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**Dr. David Mossler**

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Our cardiovascular genetic counselors serve as individual and family resources, serving as bridges to connect affected or at-risk people with optimal care by experts. From newborns to adolescents to young and older adults alike, managing genetic heart disease requires teams to coordinate their efforts. We are fortunate to have the ability to care for children and adults across the spectrum, requiring multidisciplinary, coordinated efforts between our genetic counselors, family medicine, and pediatric and adult cardiology colleagues at our center.

Our 31-year-old was later evaluated in our Advanced Lipid Clinic by our team, including lipidologist Dr. Julie Clary, who diagnosed him with dual diagnoses of elevated lipoprotein(a), or Lp(a), and familial hypercholesterolemia. Thankfully, his advanced therapies have been successful and will reduce his heart disease risk, keeping him healthy for many years to come. But there is more work to be done; there are several at-risk relatives who would benefit from risk assessment, access to diagnostic testing, and care. With encouragement and family-centered focus, we discovered later that his daughter's LDL cholesterol was very

high, even at age 2—after completing cholesterol testing beginning at this age and as recommended by guidelines from the American Academy of Pediatrics and National Lipid Association.

“What do we do from here, what does this mean for her?” he asks. Thankfully, we have colleagues in the Riley Preventive Cardiology Clinic who focus on managing and treating genetic forms of high cholesterol in children. Studies confirm that children diagnosed with familial hypercholesterolemia and optimally treated by adolescence can expect to have normal lives with greatly reduced risk of heart disease. “How can I get this information to my family? This is so important.” So, we worked on contacting relatives, routing them for evaluation and care—and we discovered several other relatives diagnosed with high cholesterol whose dietary interventions were unsuccessful.

Our work is ongoing, and thankfully, we have the multidisciplinary care models and teams to make family-based care across the lifespan—and disease preventions—a reality.●

*Helm is a genetic counselor and epidemiologist in the Cardiovascular Genetics program at IU Health.*

## American Heart Month February 2026 Events

### February

#### Kids Heart Challenge

Students at more than 400 schools in Indiana will begin participating in the American Heart Association's Kids Heart Challenge program. During the program students will get moving with fun activities, learn about keeping their hearts and brains healthy and feel great about helping others. Learn more at [heart.org/schools](http://heart.org/schools).

and tag @AHAIndiana on Facebook, Twitter or Instagram.

### February 7-14

#### Congenital Heart Defects Awareness Week

Congenital heart defects affect nine of every 1,000 births and are one of the leading causes of death for infants less than 1 year of age.



Thanks to years of research and medical advancements many congenital heart defects can be fixed.

### February 2-3

#### Heart Health Awareness Nights with the Indiana Pacers

The American Heart Association and Ascension St.Vincent will offer free Hands-Only CPR trainings during the Indiana Pacers games that kick off Heart Month.



### February 6

#### National Wear Red Day

On National Wear Red Day, thousands of people, including employees at more than 10,000 companies across the country, will wear red to support the start of American Heart Month. This year is the 25th annual National Wear Red Day. Post a picture of yourself wearing red using the hashtag #IndyGoesRed

### February 27

#### Go Red for Women Experience

The 22nd annual Go Red for Women Experience is the cornerstone event of the Go Red for Women campaign, celebrating achievements in helping



women live longer, healthier lives. This year attendees will learn the lifesaving skill of Hands-Only CPR while hearing from heart disease survivors and local leaders. For more information, visit [www.heart.org/indygoesred](http://www.heart.org/indygoesred).