



Mending Broken Hearts

A pediatric cardiologist explains how problems happen and how far we've come in treating them.

by DARSHAK SANGHAVI, M.D.

photographs by
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The day he was born via cesarean section, Alex Koravos looked perfect to his parents, Jodi and Jason, who held him closely and then passed him around to their relatives gathered in the hospital room in Worcester, Massachusetts. After a while, Alex was taken to the nursery for shots and an initial assessment.

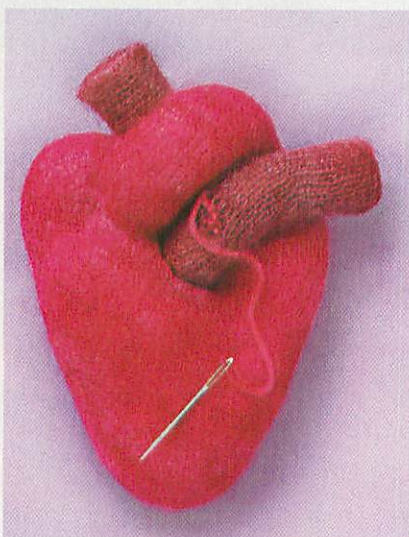
Jodi knew something was wrong when the doctor came back into her room with a stricken look. Alex seemed to have developed trouble breathing, the pediatrician said, and more

worrisome, his nail beds appeared blue instead of the usual baby-pink. The doctor didn't offer any theories, but said Alex would need more testing. The next moments passed in a blur: "I'd done everything by the book. I couldn't believe this was happening to my baby, and I was so scared," says Jodi. As a social worker involved with babies of drug-addicted mothers, she'd seen firsthand how some women took serious risks during their pregnancy, and she had been vigilant about her own health during hers. An emergency team was called

and little Alex was packed up for an ambulance ride to the newborn intensive care unit at a bigger hospital where I work as a pediatric cardiologist.

I met Alex when he arrived in the intensive care unit. I glided an ultrasound probe over his chest, and the problem was clear on the screen: A key valve within his heart had never formed, leading to a critical blockage of blood flow. In the womb, a mother's umbilical cord supplies oxygen-rich blood to a baby's heart, which in turn must pump the blood to his developing vital organs. But the moment the umbilical cord is cut at birth, a baby can no longer depend on his mother for oxygen. His first breath unfurls his lungs, and they fill with precious air. Immediately, his heart sends in blood to absorb the gas. From the lungs, blood returns to the heart, which then pumps the blood to his organs. Because this begins only after a baby leaves the womb, many serious heart problems aren't spotted until after birth.

Alex would have died in a few hours if his defect had gone undetected and untreated. We stabilized him with medications, and a team of surgeons



rebuilt his heart. He required a second surgery four months later, and he's due for a third this summer. But nearly 18 months after his rocky entrance into the world, "Alex has hit all of his developmental milestones," says Jodi. "He's a miracle baby."

Alex's story illustrates the scary way that a baby's heart problem can come seemingly out of nowhere. But over the past few years, we've made great strides in fixing conditions that had been fatal not long ago. We're also starting to understand how defects can be prevented during pregnancy. All of these advances offer real hope for families affected by heart issues.

why it happens

In the first few weeks of pregnancy, a microscopic tube of cells in a developing baby loops and twists like a balloon animal to form the heart. This delicate process goes wrong in roughly 40,000 births each year, resulting in a congenital heart defect (we don't have statistics on how many cases are detected in utero). Some are very mild, like mitral valve prolapse, and need no treatment, while other defects—like Alex's—can be serious.

The risk is higher when a pregnant woman has epilepsy, poorly controlled diabetes, or a relative with a heart defect, or if she's had repeated exposure to marijuana or organic solvents like paint thinner, or become infected with an illness such as flu or German measles. Certain medications, including some antibiotics and ibuprofen, can cause heart problems during gestation, which is why pregnant women should check with their doctor before taking any kind of drug. In some cases, a heart defect is a sign of a more complex underlying disorder in the baby, like Down syndrome or another genetic problem. Most of the time, however, we never figure out the precise cause.

pinpointing a problem

Ideally, defects are spotted before birth. Pregnant women generally have a routine, full-anatomy ultrasound during the second trimester, which can identify some heart abnormalities. Unfortunately, studies show that approximately 70 percent of cases of congenital heart defects are missed, because even major problems can be hard to spot. Women who are at particularly high risk (like those who have hard-to-control diabetes or another child with a cardiac defect) get referred to a pediatric cardiologist about halfway through their pregnancy and have a more precise heart scan called a fetal echocardiogram.

Children and Heart Murmurs

When a pediatrician listens to a child's heart with a stethoscope, she hears a "lub-dub" sound of the valves opening and closing with each beat. In some children, though, there's an extra noise, so the doctor hears "lub-whoosh-dub." This extra "whoosh" is called a murmur. In many cases, the murmur's not a problem and is simply the sound of blood being pumped through

a healthy heart. The sound may also be from a blockage or another structural heart defect. A skilled pediatrician can often tell what's normal and abnormal. If she's unsure, she can refer the child to a pediatric cardiologist for more specialized testing. In general, if a child is growing well and has no breathing problems, his heart murmur is deemed

"innocent" and requires no further testing. It's not necessarily bad news even if there's an actual heart defect: Small holes between chambers of the heart, known as atrial or ventricular septal defects, often disappear over time without any treatment. Unusual cases, such as large holes or serious problems with heart valves, typically require surgery.

Preventing Heart Defects

Most important for expectant mothers? **A daily multivitamin.** However, a lot of women don't realize that they only work to prevent birth defects when you take them at least a month before conception. Because most pregnancies are unplanned, all women capable of bearing children should take a daily multivitamin just to be safe, even if they're not trying to conceive. Fortunately, folic acid, the key

ingredient that prevents birth defects, is found in almost every multivitamin you can buy, not just prenatal ones.

Before conceiving, women should make sure they're up-to-date on the rubella (German measles) vaccine, since it must be given before pregnancy. **It's safe to get a flu shot,** so moms-to-be should be immunized too. If you develop diabetes during pregnancy, be sure to **pay close attention to your blood**

sugar; persistently high levels are known to cause birth defects. Finally, discuss any medicines—even over-the-counter ones for headaches and colds—with your doctor to ensure they're safe during pregnancy. (And this isn't limited to the first trimester: ibuprofen, for instance, can cause a key blood vessel to shut too early, even in the second and third trimesters, possibly leading to heart damage.)

Because it's so easy for heart defects to be missed before birth, in 2011 Kathleen Sebelius, the U.S. Secretary of Health and Human Services, recommended that all newborns be checked for critical congenital heart disease. The screening device most widely used is called a pulse oximeter. Right after birth, a small clip is placed on a baby's toe and palm. The clip painlessly measures the blood oxygen level, which is low in children with serious heart defects that require emergency treatment. Studies have shown that this practice saves lives, and some states, like New Jersey and Maryland, have already passed laws mandating the test. All parents should ask for it before leaving the hospital.

Despite proper fetal ultrasounds and the oxygen test at birth, however,



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some kinds of heart defects can still evade detection, and a doctor may suspect one later if a toddler has a heart murmur (see "Children and Heart Murmurs" on page 56).

Thankfully, most murmurs are benign or suggest milder defects than those diagnosed during infancy, and sometimes need no treatment.

nice treatment news

Babies who have a major heart defect may need surgery within hours of birth. I understand how stressful this is for parents. But it's comforting to know that top pediatric cardiac surgery centers that track their outcomes show that almost 100 percent of kids with the most common cardiac defects have low rates of serious complications. Several centers post their results online for parents.

In some situations, heart defects can be repaired without surgery. Using special instruments inserted into a blood vessel in the leg or arm, pediatric cardiologists can sometimes open a blockage or seal holes in the heart, in the same way that a plumber inserts a snake into a blocked drain. (This is called cardiac catheterization.) After this, or even after open-heart surgery, many kids leave the hospital in good condition within a week, which is pretty remarkable. I recently diagnosed a 15-year-old girl with a severe blockage in her aorta that was causing high blood pressure. She had an angioplasty to prop open her aorta; she went home the next day. She'll need an ultrasound every year or two—but she is likely cured.

A small number of children have very complex heart defects that need multiple surgeries during childhood. For example, some kids are missing entire pumping chambers of the heart. In rare cases, when repair isn't an option, babies and young children need a heart transplant. Most kids

survive these conditions but, sadly, they often face many lifelong medical challenges.

older kids' hearts

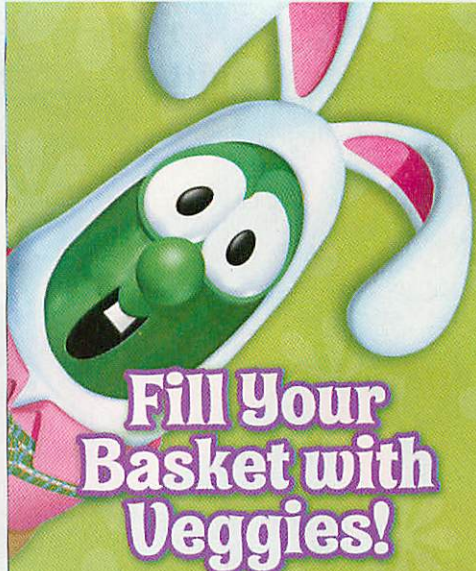
Children can develop heart problems later in life; some of those issues can cause sudden death in previously healthy children and teens. The Mayo Clinic has done a breakdown of these deaths: Roughly half are from a condition called hypertrophic cardiomyopathy, a quarter are due to unexpected problems with coronary arteries, and many of the others are the result of inherited heart-rhythm disorders. Experts argue that all teenagers should have a screening electrocardiogram, or EKG, to check for these problems, but this strategy is controversial. (It's standard for kids in Japan and Italy, and I think it's a smart idea.)

Some people propose that automated external defibrillators, or AEDs, be available at sporting events, since that's where many sudden deaths in kids occur. When Tyler Symes, another patient from our medical center, collapsed at a hockey rink in 2010, bystanders used an AED to shock his heart. His father, Ben, credits their quick actions for saving Tyler's life. (A handful of states require AEDs in schools; I hope more follow suit.)

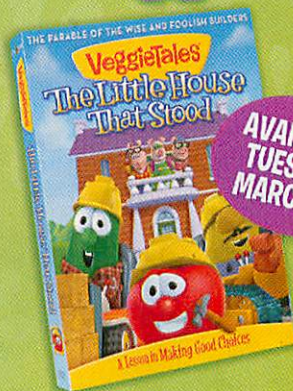
Despite the hardships facing kids with heart problems, tremendous progress has been made in the past few years. Jodi Koravos looks to the future with optimism, though her son's struggle is not over. "Alex has come such a long way," she says, "and he's a fighter." ☺

there's more!

Go to 4hcm.org/assessment to take a brief quiz that can help determine your child's risk for a sudden cardiac problem.



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