BACKGROUND: Congenital heart defects (CHDs) are problems with the heart’s structure that are present at birth. Examples include holes in the inside walls of the heart and narrowed or leaky valves. In more severe forms of CHDs, blood vessels or heart chambers may be missing, poorly formed, and/or in the wrong place. CHDs are the most common birth defects and occur in almost 1% of births. An approximate 100-200 deaths are due to unrecognized heart disease in newborns each year, and nearly 40,000 infants in the U.S. are born each year with CHDs. Approximately two to three million individuals are thought to be living in the U.S. with CHDs. Only 15-20% of all CHDs are related to known genetic conditions, and most are thought to be caused by a combination of genes and other risk factors, such as environmental exposures and maternal conditions. Because the heart is formed so early in pregnancy, the damage may occur before most women know they are pregnant.

RISK FACTORS: Most CHDs result from problems early in your child’s heart development, the cause of which is unknown. Having rubella during pregnancy can cause problems in your baby's heart development. However, your doctor can test you for immunity to this viral disease before pregnancy and vaccinate you against it. You can reduce the risk of CHDs by carefully controlling your diabetes before attempting to conceive and during pregnancy. Gestational diabetes generally doesn't increase your baby's risk of developing a heart defect. Medications known to increase the risk of CHDs include thalidomide (Thalomid), angiotensin-converting enzyme (ACE) inhibitors, statins, the acne medication isotretinoin (Absorica, Amnesteem, Claravis) and lithium. Avoid alcohol and smoking during pregnancy because these increase the risk of CHDs. Finally, CHDs sometimes run in families and may be associated with a genetic syndrome. Many children with Down syndrome, which is caused by an extra 21st chromosome (trisomy 21), have heart defects. A missing piece (deletion) of genetic material on chromosome 22 also causes heart defects. Genetic testing can detect such disorders during fetal development.

ADVANCEMENTS IN CHD CARE: Advancements in surgical and non-surgical care for congenital heart conditions are allowing children and adults with the disease to live longer, healthier lives. "Now that we have the ability to examine the effects of congenital heart disease at the molecular level, we are developing new treatments that target those changes," University of Minnesota Health Pediatric Cardiologist Jamie Lohr, MD, said. The field is also evolving in the direction of mechanical device support that helps survivors as they age. University of Minnesota Health Heart Care experts are leading the way in this area of research, particularly with ventricular assist devices (VAD). These devices help a person’s heart work better, improving quality of life or serving as a bridge to a heart transplant. New medicines are continually being developed as well as ways to adapt adult therapies for use with younger patients. The university has also developed a comprehensive care program that begins when a patient is a teenager and continues as they transition into independence and adulthood.

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