Medical Xpress

20-year study suggests return to play is manageable for athletes with most genetic heart diseases

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Receiving the diagnosis of a genetic heart disease such as long QT syndrome, which can cause sudden cardiac death, has long been a game-

ender for young athletes. But a 20-year study at Mayo Clinic following such athletes who were allowed to return to play suggests that the risks can be managed through a shared decision-making process. The retrospective study findings will be presented at the annual meeting of the Heart Rhythm Society on Tuesday, July 27, and simultaneously published in the *Journal of the American College of Cardiology*.

In the cohort studied were 672 patient athletes with genetic heart diseases that predisposed them to disease-triggered sudden cardiac arrest. Of these athletes, 495 had long QT syndrome, a genetic heart disease that can cause fainting, seizures, sudden cardiac arrest and even sudden cardiac death.

In over 2,000 combined years of follow-up, no deaths were related to sports in the athletes diagnosed with genetic heart disease who decided to return to play. Breakthrough cardiac events — fainting due to arrythmia, seizures, symptomatic ventricular tachycardia, and appropriate shocks from their implantable cardioverter-defibrillator (ICD) occurred during and beyond sports, but these events were not fatal. Most of the athletes did not have an ICD. Of those, none required a rescue shock from an external automatic defibrillator, even though that equipment was part of every athlete's safety gear and emergency action plan. These data show that athletes in the cohort had just over a 1% chance of having a nonlethal episode during sports each year.

Outcomes were categorized into two groups: athletes with long QT syndrome and athletes with other genetic heart diseases known to cause sudden cardiac arrest. Specifically, 29 patients had one or more breakthrough cardiac events associated with their long QT syndrome. Fifteen of these were athletes at the time, and three had a sports-related cardiac event. In the 177 patients with other genetic heart diseases, including hypertrophic cardiomyopathy and catecholaminergic polymorphic ventricular tachycardia, 14 nonlethal cardiac events

happened during the return-to-play time.

The study is a continuation of research on return to play that Michael J. Ackerman, M.D., Ph.D., first published in *JAMA* in 2012. Dr. Ackerman is a genetic cardiologist, and he directs the Windland Smith Rice Genetic Heart Rhythm Clinic at Mayo Clinic.

"When I joined Mayo Clinic's staff in 2000, we rejected the prevailing approach to athletes with genetic heart diseases that was embraced throughout the world: 'If in doubt, kick them out.' After seeing the demoralizing and destructive effects of disqualification on athletes, we decided to embrace a shared and informed decision-making process," says Dr. Ackerman.

Shared decision-making for a return to play has important steps that Dr. Ackerman says are critical to the success of the process. This begins with thorough testing, a customized treatment plan, discussion of risks and a review of current guidelines for sports participation. If the athlete and parents are unanimous in their decision—when age-appropriate—return to play is allowed. Then coaches and school officials are informed and safety measures put in place, including having a personal automatic electronic defibrillator, avoiding QT-prolonging drugs in the case of long QT syndrome, maintaining proper hydration and electrolyte balance, and having annual follow-up consultations with their genetic cardiologist for risk reevaluation and treatment review.

The study included athletes participating in organized, competitive sports between July 1, 2000, and July 31, 2020. Each athlete's record was reviewed for clinical details, treatments, breakthrough cardiac events and the sport or sports played. The most physically active sport of each athlete was used to classify individual risk level. Interestingly, no striking difference in event rate was based on sports classification. The return-to-play time was unique to each athlete, calculated as the time

when each athlete participated in sports following evaluation and approval to resume playing.

"The results of implementing shared decision-making have been incredibly satisfying and in fact have reshaped the global conversation for athletes with a wide variety of genetic heart diseases," says Dr. Ackerman. "Young people with genetic heart disease can grow up and dream big. Such athletes will be able to reach for the highest level of Olympic and professional sports."

However, Dr. Ackerman cautions that this approach is not a universal solution. For some athletes, the shared decision-making process culminates in a recommendation to stop their sport of choice. This is the case for athletes who have a specific type of genetic heart disease that accelerates with sports activity. He said 15%–20% of his athletic patients come to a family-based decision of sports disqualification after evaluation. So not everyone chooses to return to play when the option is presented.

More information: Kathryn E. Tobert et al, Return-to-Play for Athletes With Long QT Syndrome or Genetic Heart Diseases Predisposing to Sudden Death, *Journal of the American College of Cardiology* (2021). DOI: 10.1016/j.jacc.2021.04.026

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