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For Immediate Release

Sports Guidelines for Long QT Syndrome Patients May be too Strict, Mayo Clinic Finds

Finding comes as Olympic swimmer with condition prepares to compete

ROCHESTER, Minn. — Participation in competitive sports by people with long QT syndrome — a genetic abnormality in the heart's electrical system — has been a matter of debate among physicians. Current guidelines disqualify most LQTS patients from almost every sport. In a first-of-its-kind study, Mayo Clinic's LQTS Clinic recently examined its own experience, determining the outcome of LQTS patients who chose to remain athletes against guideline recommendations. The study is published online in the *Journal of the American Medical Association.*

In the study, the records of 353 LQTS patients ages 6 to 40 who were evaluated at Mayo Clinic between July 2000 and November 2010 were reviewed to determine which patients chose to continue athletic participation after LQTS diagnosis and LQTS-related events.

Of the 157 patients who were athletes at the time of their evaluation, 27 (17 percent) chose to disqualify themselves, "debunking the myth" that families would never choose to quit sports, says senior author Michael Ackerman, M.D., Ph.D., pediatric cardiologist and Director of Mayo's LQTS Clinic. More importantly, of the 130 patients who chose to remain an athlete, only one experienced a LQTS-triggered event during a sport; the athlete received an appropriate shock from his implantable cardioverter-defibrillator on two separate occasions. For the study, researchers defined a competitive athlete as a person who participated in organized competitive sports at the little league, middle or high school, collegiate or professional level.

"About eight years ago after I started to see some of these lives ruined by the recommendation to discontinue sports, we decided to challenge the status quo," Dr. Ackerman says. "We adopted a philosophy that empowered patients and their families with the right to make an informed and difficult decision about continuing in competitive sports, a known LQTS-established risk-taking behavior."

Dr. Ackerman presented these findings Sunday in Glasgow, Scotland, at a pre-2012 Summer Olympics medical conference on sports, athletes and health. LQTS patients can become successful athletes; swimmer Dana Vollmer, who has LQTS and is not a Mayo patient, will compete in London.

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In LQTS, which affects one in 2,000 people, the rapid heartbeats can trigger a sudden fainting spell, seizure or sudden death. Treatment can involve medication, medical devices or surgery.

"We felt that although exercise, sports, and the thrill of victory and agony of defeat could potentially trigger a dangerous heart rhythm in these patients, that in a well-counseled, well-studied and well-treated patient, these may be manageable risks," Dr. Ackerman says. "Up until now, the current status quo has been to view these things as controllable risk factors which are controlled by kicking these patients out of most sports and telling them to not get their heart rate up and not get too excited."

Two sets of guidelines have medical eligibility criteria for patients with cardiovascular abnormalities: the 36th Bethesda Conference guidelines and the European Society of Cardiology guidelines. The ESC guidelines are more restrictive, Dr. Ackerman says. Both sets of guidelines are based on expert opinions and rely on the "art of medicine" because there is little evidence about the real risk of sports participation, he says.

As patients in Mayo Clinic's LQTS Clinic, all 353 initially evaluated for this study received a comprehensive two- to three-day clinical and genetic evaluation, including a one- to two-hour consultation with Dr. Ackerman, all of which is standard for LQTS Mayo patients.

Patients who were already athletes and chose to continue athletics received counseling on athletic participation guidelines. If the patient chose to continue competitive athletics, the decision had to be agreed on by the physician, the patient, and both parents, depending on the patient's age. In addition to the patient's treatment, such as medications, each athlete obtained an automated external defibrillator, and the athlete's school officials and coaches were notified.

Of the 130 patients who remained athletes, 20 had ICDs. Forty-nine (38 percent) participated in more than one sport. Thirty-two athletes competed in high school, and eight competed at the college, university or professional level.

The results suggest that the Bethesda and ESC guidelines may be excessively restrictive, Dr. Ackerman says. But he cautions that LQTS patients who want to remain athletes should seek treatment at a center of excellence. "The patient must be evaluated, risk-stratified, treated, and counseled carefully so that the athletes and their families can make an informed decision," he says.

Jonathan Johnson, M.D., is the first author of the study. Dr. Ackerman is the Windland Smith Rice Cardiovascular Genomics Research Professor at Mayo Clinic. The research was funded by the Mayo Clinic Windland Smith Rice Comprehensive Sudden Cardiac Death Program.

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