

European Reference Network (ERN) Heart Gateway to Uncommon And Rare Diseases of the Heart (ERN GUARD-Heart)

PARTICIPATION OF PATIENTS WITH LONG QT SYNDROME IN SPORTS

In this project, healthcare professionals are invited to seek advice for their patients with long QT syndrome (LQTS) with regard to their participation in sports. The healthcare professionals can do this by entering their patients with LQTS diagnosis who (aims to) participate in sports into the Clinical Patient Management System (CPMS)*, by uploading a case report form (CRF) and an ECG and invite members of an advisory panel to provide recommendations.

Current members of the ERN GUARD-Heart advisory panel for this project are: Elijah Behr, Antoine Leenhardt, Anita Hiippala, Pier Lambiase, Jacob Tfelt-Hansen, and Arthur Wilde.

- ➔ For each patient, the referring physician should upload at least a 12-lead ECG at baseline (and preferably during an exercise test). In addition, the referring physician is requested to answer the questions on the case report form and upload the form in the CPMS.

There are no criteria with regard to age, sex, and/or ethnicity for patient inclusion.

The recommendations of members of the advisory panel should at least address the next question: should the patient with the LQTS diagnosis limit or restrict his/her participation in sports? If yes:

- to what limit should participation in sports be restricted (answer minutes/hours per week)
- which type of sports is the patient yet allowed to perform (please check the white box for the appropriate sports category in table 1)?

All cases entered into the CPMS for this project will be collected in a database for future research. The advisory panel will officially start on 1 September 2019, but uploading the cases is possible from 1 August 2019.

** For instructions how to gain access to CPMS and/or enter a patient into the CPMS, please contact the CPMS-helpdesk of the ERN GUARD-Heart (email: cpmshelpdesk@guardheart.ern-net.eu; phone: +31 6 45153319) or the project management office (<http://guardheart.ern-net.eu/about/contact/>).*