



### European Reference Network (ERN)

### 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)\* 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 entered into the CPMS, 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 address the following questions:

- Has genetic testing been performed in the patient? If yes, which genes have been tested and what was the result of genetic testing (please include affected gene, variant and assignment).
- Has the patient experienced symptoms? If yes, please specify (e.g., cardiac arrest, syncope, documented arrhythmia, palpitations)?
- Does family history include (aborted) sudden death or cardiac arrest at age <45 years? If yes, did this occur during sports activity?
- Does the patient use any cardiac or non-cardiac drugs?
- Which sports does the patient primarily perform?
- Does the patient perform any secondary sports? (>3 hours per week)? If yes, which?
- How many hours per week does the patient train and compete?
- How many years has the patient been training at a comparable level?
- The patient trains at the following level (multiple choice):
  - Recreational
  - Recreational with competitions
  - Competitive national
  - Competitive international
- On which treatment is the patient (e.g., beta-blocker, ICD, left stellate ganglion block)?
- What is the maximal heart rate of patient during a maximal exercise test (on treatment??)?
- What is the maximal capacity of patients during a maximal exercise test? (*answer numbers and unit, i.e. Watts, km/h, VO<sub>2</sub>max, and METS*)

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



# European Reference Network

for rare or low prevalence complex diseases

**Network**  
Heart Diseases  
(ERN GUARD-HEART)

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. Patient enrolment will start on 1 June 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](mailto:cpmshelpdesk@guardheart.ern-net.eu); phone: +31 6 45153319) or the project management office (<http://guardheart.ern-net.eu/about/contact/>).

**Table 1**

Increasing Static Component ↑ III. High (>50% MVC) II. Moderate (20-50% MVC) I. Low (<20% MVC)	Bobsledding/Luge*†, Field events (throwing), Gymnastics*†, Martial arts*, Sailing, Sport climbing, Water skiing*†, Weight lifting*†, Windsurfing*†	Body building*†, Downhill skiing*†, Skateboarding*†, Snowboarding*†, Wrestling*	Boxing*, Canoeing/Kayaking, Cycling*†, Decathlon, Rowing, Speed-skating*†, Triathlon*†
	Archery, Auto racing*†, Diving*†, Equestrian*†, Motorcycling*†	American football*, Field events (jumping), Figure skating*, Rodeoing*†, Rugby*, Running (sprint), Surfing*†, Synchronized swimming†	Basketball*, Ice hockey*, Cross-country skiing (skating technique), Lacrosse*, Running (middle distance), Swimming, Team handball
	Billiards, Bowling, Cricket, Curling, Golf, Riflery	Baseball/Softball*, Fencing, Table tennis, Volleyball	Badminton, Cross-country skiing (classic technique), Field hockey*, Orienteering, Race walking, Racquetball/Squash, Running (long distance), Soccer*, Tennis
	<b>A. Low (&lt;40% Max O<sub>2</sub>)</b>	<b>B. Moderate (40-70% Max O<sub>2</sub>)</b>	<b>C. High (&gt;70% Max O<sub>2</sub>)</b>
	Increasing Dynamic Component →		