



European Reference Network

for rare or low prevalence complex diseases

Network
Heart Diseases
(ERN GUARD-HEART)

Sports participation of patients with Long QT Syndrome

Case Report Form

Pseudonomized ID

..... (for example AMC001)

Gender:

- Male
- Female

Year of Birth:

.....

1a. Has genetic testing been performed?

- Yes
- No

1b. If yes:

which genes have been tested?

- KCNQ1, KCNH2, SCN5A
- KCNQ1, KCNH2, SCN5A, KCNE1, KCNE2
- AKAP9, ANK2, CACNA1C, CALM1, CALM2, CALM3, CAV3, KCNE1, KCNE2, KCNH2, KCNJ2, KCNJ5, KCNQ1, SCN4B, SCN5A, SNTA1, TRDN.
- Other:

Was deletion/duplication analysis performed:

- Yes
- No

2. Results of genetic testing :

(please include affected gene, variant and assignment)

.....

3a. Has the patient experienced symptoms?

- Yes
- No

3b. If yes: please specify and include circumstances (e.g. cardiac arrest, syncope, documented arrhythmia, palpitations)

.....

4a. Does family history include (aborted) sudden death or cardiac arrest at age < 45?

- Yes
- No

4b. If yes: please specify age during event and family relation to patient:

.....

4c. If yes: what were the circumstances during the cardiac arrest?

.....

5a. Does the patient use any cardiac drugs?

- Yes
- No

5b. If yes: please specify:

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6a. Does the patient use any non-cardiac drugs?

- Yes
- No

6b. If yes: please specify:

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7a. Which sports does the patient primarily perform?

.....

7b. How many hours per week does the patient respectively train and compete?

Training:

Competitive:

7c. How many years has the patient been training at a comparable level?

.....

7d. The patient trains at the following level (multiple choice)

- Recreational
- Recreational with competitions
- Competitive national
- Competitive international

7e. Please fill in the following table

| | | | |
|---|--|---|---|
| ↑ 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 <input type="checkbox"/> | Body building, Downhill skiing, Skateboarding, Snowboarding, Wrestling <input type="checkbox"/> | Boxing, Canoeing/Kayaking, Cycling, Decathlon, Rowing, Speed-skating, Triathlon <input type="checkbox"/> |
| | Archery, Auto racing, Diving, Equestrian, Motorcycling <input type="checkbox"/> | American football, Field events (jumping), Figure skating, Rodeoing, Rugby, Running (sprint), Surfing, Synchronized swimming <input type="checkbox"/> | Basketball, Ice hockey, Cross-country skiing (skating technique), Lacrosse, Running (middle distance), Swimming, Team handball <input type="checkbox"/> |
| | Billiards, Bowling, Cricket, Curling, Golf, Riflery <input type="checkbox"/> | Baseball/Softball, Fencing, Table tennis, Volleyball <input type="checkbox"/> | Badminton, Cross-country skiing (classic technique), Field hockey, Orienteering, Race walking, Racquetball/Squash, Running (long distance), Soccer, Tennis <input type="checkbox"/> |
| A. Low ($<40\% \text{ Max O}_2$) B. Moderate ($40-70\% \text{ Max O}_2$) C. High ($>70\% \text{ Max O}_2$) Increasing Dynamic Component → | | | |

8a. Does the patient perform any secondary sports (> 3 hours per week)?

- Yes
- No

b. If yes, which?

.....

9. Is the patient on additional treatment? (e.g. ICD, left cardiac sympathetic denervation?)

.....

10a. What is the maximal heart rate of the patient during a maximal exercise test?

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10b. Was this on treatment?

.....

10c. What is the maximal capacity of the patient during a maximal exercise test? (answer numbers and unit, i.e. Watts, Km/h (or VO₂max), and METS).

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Consultation requested by (name):

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Date:

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Additional information:

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