

Tuesday 06 August 2019

ERN

GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart



ERN GUARD-HEART BIMONTHLY NEWSLETTER

YEAR 2019 NUMBER 4

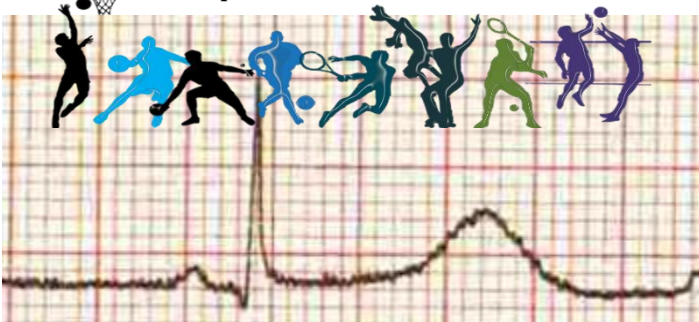
Update Long QT Syndrome & Sports

Amsterdam, 01 August 2019

In this project of the ERN GUARD-Heart, healthcare professionals are invited to seek advice for their patients with long QT syndrome (LQTS) with regard to participation in sports. Healthcare professionals can do this by entering their patients with LQTS diagnosis who (wish 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, Lia Crotti, 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 fill in the digital Case Report Form (CRF) and upload it in CPMS. This CRF is also available for download on our ERN website (see [link](#)): Enrolment of patients in CPMS can start from now, the advisory panel will start their work on 1 September. ♥



Educational videos by ERN GUARD-Heart experts

Amsterdam, 01 August 2019

ERN GUARD-Heart has started to produce online educational videos for healthcare professionals who wish to gain more detailed knowledge on rare cardiac diseases & different aspects of multidisciplinary management of these diseases, e.g., next-generation sequencing, sports, pregnancy. The first two educational videos are now available on the official ERN website (see [link](#)). The management office is currently creating a list of topics and candidate speakers. Next, candidate speakers will be asked whether they are willing to participate. The videos will be produced & disseminated by the management office. ♥

Upcoming call for European centers to join existing ERNs

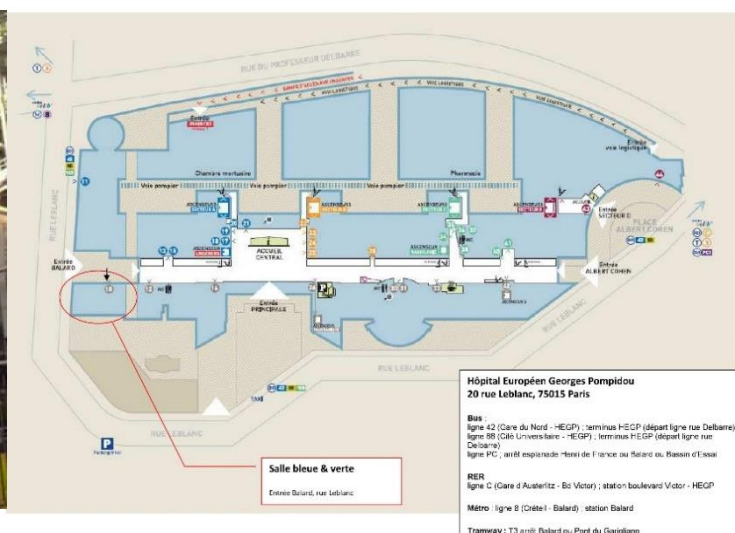
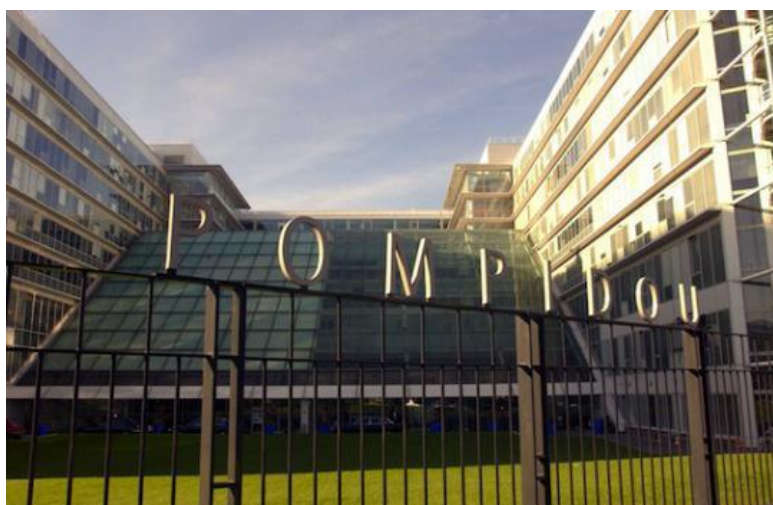
Brussels, 24 June 2019

The European Commission is currently preparing a second call for full members to join existing ERNs. The call is expected to be opened in September. ERN GUARD-Heart will be extended with two additional thematic areas: congenital heart disease and 'other rare heart diseases'. Each application will undergo and eligibility check by the EU and assessments by an independent assessment body and the specific ERN the candidate center wishes to join. It is expected that the assessment procedure & possible approval will be finalized at the end of 2020. Details are available on the European Commission website (see [link](#)). ♥



6th Board Meeting of ERN GUARD-Heart

Paris, Tuesday 3 September 2019



Amsterdam, 1 August 2019

The 6th board meeting of the ERN GUARD-Heart will be held in Paris, France, on 3 September 2019, during the congress of the European Society of Cardiology (ESC). The meeting will be held in 'Salle Bleue', Hôpital Européen Georges-Pompidou, 20 Rue Leblanc, 75015 Paris. This is 1.5 km (~20 minutes walk) from Expo Porte de Versailles (the ESC congress location). The meeting **will start at 8.30 AM** and will close with a lunch between 13.30 and 14.30 PM.

List of participants

Amin, Ahmad (*project manager*)
 Arbustini, Eloïse (*Pavia*)
 Baban, Anwar (*Rome*)
 Bauce, Barbara (*Padua*)
 Behr, Elijah (*London*)
 Biller, Ruth (*EPAG Germany*)
 Bleijendaal, Hidde (*CPMS Helpdesk*)
 Caforio, Alida (*Padua*)
 Caiazza Martina (*Naples*)
 Charron, Philippe (*Paris*)
 Chevalier, Philippe (*Lyon*)
 Costafreda, Ester (*EPAG Spain*)
 DeAsmundis, Carlo (*Brussels*)
 DeRavel, Thomy (*Brussels*)
 Denjoy, Isabelle (*Paris*)
 Drago, Fabrizio (*Rome*)
 Garcia Pavia, Pablo (*Madrid*)
 Gimeno, Juan (*Murcia*)

Hagege, Albert (*Paris*)
 Helio, Tiina (*Helsinki*)
 Hernando, Ines (*EURORDIS*)
 Hofman, Nynke (*project manager*)
 Jurcut, Ruxandra (*Bucharest*)
 Leenhardt, Antoine (*Paris*)
 Mörner, Stellan (*Umeå*)
 Napolitano, Carlo (*Pavia*)
 Pihkala, Jaana (*Helsinki*)
 Probst, Vincent (*Nantes*)
 Robyns, Tomas (*Leuven*)
 Sarquella-Brugada, Georgia (*Barcelona*)
 Schülze-Bahr, Eric (*Munster*)
 Schwartz, Peter (*Milan*)
 Tavacova, Terezia (*Prague*)
 Tfelt Hansen, Jacob (*Copenhagen*)
 Wilde, Arthur (*Amsterdam, coordinator*)



ERN Board Meeting

Agenda* of the 6th ERN GUARD-Heart Board Meeting

Based on the work plan for the 3rd ERN year

Paris, 03 September 2019

8.00 Welcome and Coffee

8.30 Opening remarks and aims of the meeting

Update on activities of the third year of the ERN (3/2019 – 2/2020)

- Deliverables of the 3rd year
- Extension of the Network
- Integration of Affiliated Partners

Educational Work Plan

- Educational video's for professionals
- Topic meetings for patients
- Fellowships Pathology and Genetics

European patient Advocacy Groups (EPAGs):

- Update on EPAGs
- PROMS – meeting
- Cardiac PATROL (App for registries and studies)
- Patient Information: need/ ideas for extra material?

11.00 Coffee-break

11.30 Official Monitoring

- Re-definition of indicators
- How to collect the information
- Deadlines
- Discussion and questions

12.15 Clinical Patient Management System (CPMS)

- Activities and experiences
- Experienced problems
- Uploading LQT-cases: advice from LQT-expert panel on sports participation

12.45 Update on registries

- Overview of current ERN-registries
- Grant for registries

13.15 Questions and closing

13.30 Lunch



Latest ERN GUARD-Heart Publications

1. van der Werf C, Lieve KV, Bos JM, Lane CM, Denjoy I, Roses-Noguer F, Aiba T, Wada Y, Ingles J, Leren IS, Rudic B, Schwartz PJ, Maltret A, Sacher F, Skinner JR, Krahn AD, Roston TM, Tfelt-Hansen J, Swan H, Robyns T, Ohno S, Roberts JD, van den Berg MP, Kammeraad JA, Probst V, Kannankeril PJ, Blom NA, Behr ER, Borggrefe M, Haugaa KH, Semsarian C, Horie M, Shimizu W, Till JA, Leenhardt A, Ackerman MJ, Wilde AA. Implantable cardioverter-defibrillators in previously undiagnosed patients with catecholaminergic polymorphic ventricular tachycardia resuscitated from sudden cardiac arrest. *Eur Heart J*. 2019 May 30. pii: ehz309. doi: 10.1093/eurheartj/ehz309.
2. Crotti L, Spazzolini C, Tester DJ, Ghidoni A, Baruteau AE, Beckmann BM, Behr ER, Bennett JS, Bezzina CR, Bhuiyan ZA, Celiker A, Cerrone M, Dagradi F, De Ferrari GM, Etheridge SP, Fatah M, Garcia-Pavia P, Al-Ghamdi S, Hamilton RM, Al-Hassnan ZN, Horie M, Jimenez-Jaimez J, Kanter RJ, Kaski JP, Kotta MC, Lahrouchi N, Makita N, Norrish G, Odland HH, Ohno S, Papagiannis J, Parati G, Sekarski N, Tveten K, Vatta M, Webster G, Wilde AAM, Wojciak J, George AL, Ackerman MJ, Schwartz PJ. Calmodulin mutations and life-threatening cardiac arrhythmias: insights from the International Calmodulinopathy Registry. *Eur Heart J*. 2019 Jun 6. pii: ehz311. doi: 10.1093/eurheartj/ehz311
3. Fellmann F, van El CG, Charron P, Michaud K, Howard HC, Boers SN, Clarke AJ, Duguet AM, Forzano F, Kauferstein S, Kayerserili H, Lucassen A, Mendes A, Patch C, Radojkovic D, Rial-Sebbag E, Sheppard MN, Tassé AM, Temal SG, Basso C, Wilde AAM, Cornel MC. European recommendations integrating genetic testing into multidisciplinary management of sudden cardiac death. *Eur J of Hum. Genet*. <https://doi.org/10.1038/s41431-019-0445-y>.




6th ERN GUARD-Heart Board Meeting
3 September 2019 (8.30 – 14.30)
Hôpital Européene Georges-Pompidou

Reminder:

**Fellowship CRY
Cardiovascular
Pathology Unit London**

**write your motivation letter before 1
september ([link](#))**

UPCOMING CARDIOLOGY EVENTS

European Society of Cardiology	31 August - 4 September	Paris – France
Update in Clinical Cardiology	16 October – 18 October	Boston – Massachusetts
Patient Meeting CPVT	9 November	Amsterdam UMC – The Netherlands
Patient and Experts PLN Meeting	28 November	Murcia - Spain

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