

Thursday 21 May 2020

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

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GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart



ERN GUARD-HEART BIMONTHLY NEWSLETTER

YEAR 2020 NUMBER 3

COVID-19 Webinars launched by the European Commission.

Amsterdam, 18 May 2020

In the context of the “COVID-19 Clinical Management Support System” launched by the European Commission, DG SANTE organizes a [series of webinars to support clinicians and other healthcare professionals](#). Based on the experience with the European Reference Networks (ERNs), these series of webinars will bring the expertise and recommendations of some of the experts of the 24 ERNs in the management of some of the more complex cases of patients suffering at the same time of COVID-19 and a rare or complex disease or conditions. ERN GUARD-Heart participated with two webinars: 23 April COVID-19 and inherited arrhythmias (Arthur Wilde, Elena Arbelo) and 7 May: COVID-19 in patients with cardiomyopathies and myocarditis (Philippe Charron, Perry Elliott, and Alida Caforio). Due to technical problems the first Webinar was not recorded. The second one, on cardiomyopathies and myocarditis is available by the following link: https://ec.europa.eu/health/ern/events/ev_20200507_en ❤️

How to manage patients affected by COVID-19 with cardiomyopathies and myocarditis?





Online patient meetings - ERN activities

COVID-19 question and answers session for patients with cardiomyopathies – Germany

Münster, 7 May 2020

Ruth Biller, the chair of the European Patient Advocacy Groups (EPAGs), and chair of ARVC Selbsthilfe, a German patient organization for patients with Cardiomyopathy/ ARVC, organized a covid-19 question and answers session for cardiomyopathy/ ARVC patients in Germany. The direct link to this recorded session: is <https://vimeo.com/416519575>. ❤



Online patient meetings for Dutch patients

Amsterdam, 19 May 2020

Amsterdam UMC organized three COVID-19 online patient meetings for respectively LQTS/CPVT (2 april), Brugada syndrome (9 april), and congenital heart disease (30 april). The slides of the presentations and the question- and answer files are available on the ERN website (all in Dutch). With about 80-110 connections per meeting and participants who had relevant questions, and a lot of positive reactions, we would like to encourage other members to organize these kind of sessions as well. ❤

Website ERN GUARD-Heart

Amsterdam, 19 May 2020

The project management team added a page to the website of ERN GUARD-heart with links and information related to covid-19. <https://guardheart.ern-net.eu/covid-19/> Please share your activities and important links with us, for publication on the website as well. ❤





Special issue EJMG ERN GUARD-Heart

Call for contribution

**PLEASE READ:
IMPORTANT
MESSAGE**

Paris, 20 May 2020

In the first newsletter of 2020 a proposal was published for ERN-specific issues in the European Journal of Medical Genetics.

The Editor Alain Verloes is also a coordinator of another ERN and he offers the opportunity to have a special issue dedicated to our ERN Guard-Heart.

The thematic area of familial cardiomyopathies responded positively on this and Philippe Charron confirmed to the editor the possible participation as Guest editor for this thematic area.

Now it would be great to add the other thematic area's as well in a joined initiative. To identify another Editor for these other areas is welcome.

Please contact the project managers (n.hofman@amsterdamumc.nl) and Philippe (philippe.charron@aphp.fr) for more information and participation.

Regarding Familial cardiomyopathies, at that stage you can already think about potential articles, reviews or case report that could be suitable.

Below the initial publication on this topic is copied from the newsletter of January 2020. ♥

Alain Verloes, coordinator of ERN ITHACA (Rare Congenital Malformations & Intellectual Disability) and editor-in-chief of European Journal of Medical Genetics (EJMG) has proposed the possibility of preparing special issues of EJMG for specific ERNs. These special issues will be planned soon. If there is interest from our Network, we should make the next steps:

- Provide the names of 2 experts from our ERN as Guest Editors with their contact details - these 2 Guest Editors will supervise the peer-review process of the articles and validate their acceptance;
- Follow a provisional deadline for the submission of papers for a first review (between mid-2020 & mid-2021).
- Provide a provisional table of contents of the issue preferably at least 4 months before deadline date.

The special EMJG issue may consist of:
journal articles on one of the themes of the ERN
recommendations for good practice
patient series
clinical trials
results of recommended therapies
comments, positions, or editorials
max. 2 or 3 very selected cases reports

Eight to 15 contributions are usually necessary (depending on number of pages per submission). The articles must be related to genetic disorders (monogenic or chromosomal diseases) or to developmental abnormalities, even non-genetic (intellectual disabilities, malformations, teratogenic). Revised versions will be expected 3 months after the deadline for the 1st submission. The maximum length of articles is 15.000 words for a review, 8.000 words for other types of articles. All accepted articles are posted online after a few days. Paper versions of special issues will be available a few weeks after the validation of the last article. Please, if you are interested to discuss this further: contact ERN GUARD-Heart management office as soon as possible. We need to confirm our participation by February 15th, with contact details of 2 Guest Editors. ♥



ERN activities

Tuesday, 1 September 2020



Our next ERN GUARD-Heart boardmeeting was planned during the ESC in Amsterdam. As expected the ESC has been canceled.

However, we still aim to organize the boardmeeting at **1 September 2020** (the original planned date). Whether it will be online or physical (at 1.5 meter distance) we haven't decided yet and it will depend of the next couple of weeks and your opinion. We will send around a questionnaire for that.♥

COVID-19 Clinical Management Support System (CMSS)

In the context of the fight against the coronavirus pandemic, the European Commission launched the COVID-19 Clinical Management Support System (CMSS). The aim is to support doctors, nurses, and other healthcare professionals in hospitals that are currently dealing with COVID-19 cases all over the EU, UK and the EEA countries. This system allows for professionals to communicate easily with colleagues, exchange knowledge, discuss cases and improve training, namely via webinars. Based on the experience with the ERNs, the initiative helps create rapid connections across Europe among all involved healthcare professionals and hospitals in the management of COVID-19. Health workers can rely on a dedicated helpdesk managed by the European Commission's Directorate-General for Health and Food Safety (DG SANTE) to set up web conferences and exchange with their peers in Europe opinions about possible treatments and about how to handle severe and complex cases. Detailed information and the the workflow of the system is available on the website of the EU: https://ec.europa.eu/health/ern/covid-19_en ♥

Latest ERN GUARD-Heart Publications

1. Mazzanti A, Guz D, Trancuccio A, Pagan E, Kukavica S, Chargeishvili T, Olivetti N, Biernacka EK, Sacilotto L, Sarquella-Brugada G, Campuzano O, Nof E, Anastasakis A, Sansone VA, Jimenez-Jaimez J, Cruz F, Sánchez-Quiñones J, Hernandez-Afonso J, Fuentes ME, Średniawa B, Garoufi A, Andršová I, Izquierdo M, Marinov R, Danon A, Expósito-García V, Garcia-Fernandez A, Muñoz-Esparza C, Ortíz M, Zienciuk-Krajka A, Tavazzani E, Monteforte N, Bloise R, Marino M, Memmi M2, Napolitano C, Zorio E, Monserrat L, Bagnardi V, Priori SG. Natural History and Risk Stratification in Andersen-Tawil Syndrome Type 1. *J Am Coll Cardiol.* 2020 Apr 21;75(15):1772-1784. PMID: 32299589.
2. Cuneo BF, Kaizer AM, Ann Clur S, Swan H, Herberg U, Winbo A, Rydberg A, Haugaa K, Etheridge S, Ackerman MJ, Dagradi F, Killen SAS, Waker-Gussmann A, Benson DW, Wilde AAM, Pan Z, Lam A, Spazzolini C, Horigome H, Schwartz PJ; Fetal LQTS Consortium. Mothers with long QT syndrome are at increased risk for fetal death: Findings from a multicenter international study. *Am J Obstet Gynecol.* 2020;222:263.e1-11. PMID: 31520628.

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