

Friday 17 July 2020

ERN



GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart

ERN GUARD-HEART BIMONTHLY NEWSLETTER

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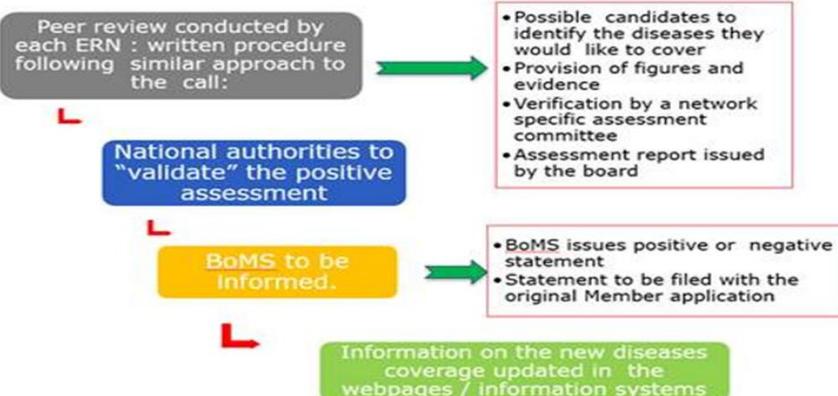
Expansion of expertise areas for current ERN members

Amsterdam, 17 July 2020

Upon the call of the European Commission (EC) for new healthcare providers (HCPs) to apply to become members of the ERNs (opened between 30 September & 30 November 2019), ERN GUARD-Heart has added, as planned from the start, two thematic areas, i.e. 'congenital heart diseases' and 'other rare cardiac diseases'. All applicants were able to apply for these new disease areas. Related to this, existing members of ERN GUARD-Heart will also have the opportunity to apply for these new thematic areas. In order to officially update the disease coverage of the existing ERN members, and to validate their fulfilment to the specific criteria and the minimum numbers of patients and procedures, the ERNs, in collaboration with the EC, have designed an application process (*see figure below*). This procedure includes a peer review by the Network Boards and validation of a positive assessment of the Network Boards by National authorities and the Board of Member States. The Commission has suggested a "light-touch" assessment process for the existing members; i.e., HCPs are already compliant with the general EU criteria for ERN membership, and only additional teams within the HCPs that aim to be included in the new thematic areas need to be assessed as new candidates. This light-touch procedure will include 3 steps, as is the case for new members, i.e. 1. Internal review by the ERN, including engagement with patient organisations; 2. A letter from the national health authorities to approve expertise in the new areas; and 3. A validation from the Board of Member States confirming that HCP's have expertise in the new areas.

The initial step in the process for existing ERN GUARD-Heart members is to identify any changes to disease areas they wish to cover and to provide details of these changes, along with the appropriate numbers and evidence to the project management office. A proposal template which can be used for this is currently under construction and will be shared as soon as available. ♥

(b) ensuring the disease coverage for previous Member of the Network and proposals





Transversal cross-ERNs Working Group on Pregnancy and Family Planning in rare, low-prevalence and complex diseases

Join the Group!



Pisa, 13 July 2020

Professor Marta Mosca, coordinator of ERN ReCONNET (ERN for Rare and Complex Connective Tissue and Musculoskeletal Diseases) from Pisa, has initiated a transversal cross-ERNs working group on pregnancy and family planning in rare, low-prevalence and complex diseases. The working group will be constituted by representatives of each ERN, taking care of driving the research in this field, delivering specific clinical practice guidelines for pregnancy planning and management in rare diseases, as well as develop education and information materials for patients and healthcare professionals. In addition, it could be envisaged to create a transversal registry of pregnancy in rare disease with the main aim of collecting European-wide evidence on the management of this specific condition.

So far, 22 ERNs have expressed their interest in joining the working group. In order to keep the group manageable it was agreed that all ERN coordinators will identify 3 persons to be included in the working group for their ERN: an medical expert, a patient representative and the coordinator. An online cross-ERN workshop will be organized ideally within the end of the year.

- If you are interested to join this working group (as medical expert or as patient representative), please send an e-mail to the project management (n.hofman@amsterdamumc.nl) before 25 July 2020. This is not necessary if you responded already to this question in the survey.
- Furthermore, possible topics that could be addressed during the cross-ERN workshop are currently being collected now, so please let us know if you have any suggestions. ♥

Topic Meetings for Patients

Amsterdam, 17 July 2020

In this fourth ERN year (2020-2021), there is a budget for 10 national meetings for patients (in different countries). Due to COVID-19 pandemic, none of the planned meetings (Spain, Netherlands, Belgium, France, and Germany) have been held. However, few COVID-19-related information sessions were organized for patients. So, there is still a budget for patient meetings (the fourth ERN year ends on 28th of February 2021, and this also count for the financial part); so preferably, the meeting should be planned before the end of 2020). Although we don't know if this is feasible yet in your Member State, please contact us for financial support if you would like to organize a patient meeting. ♥

Educational videos for professionals

Amsterdam, 17 July 2020

During the last year, ERN GUARD-Heart published 8 educational videos. These videos have been created for healthcare professionals who wish to gain more knowledge on rare cardiac diseases and different aspects of multidisciplinary management of these diseases. The videos are available on YouTube (<https://www.youtube.com/watch?v=dIcR8WmsR6M>) and on the official ERN website: <http://guardheart.ern-net.eu/experts/educational-videos/>. A list of additional topics and speakers has already been proposed during the Board meeting in September 2019 and presenters have been re-contacted or will be contacted by the project managers for the planning and technical assistance to produce the videos. ♥



PROMS / PREMS workshop ERN GUARD-Heart

Call for contribution to the online query

Brussels, 15 July 2020

The University Hospital Brussels is preparing a one-day workshop on Patient Reported Outcome/Experience Measures (PROMS/PREMS). This will be probably held in the second half of October 2020. It has not yet been decided whether the meeting will be face-to-face or remote/online. If it will be a face-to-face meeting, it will be most likely organised at the airport of Zaventem-Belgium.

To prepare for the workshop, the team of the University Hospital Brussels kindly requests (*through the email below*) **all ERN GUARD-Heart members** to complete a survey on their currently available psycho-social support workflows and questionnaire:

Dear Colleagues,

In collaboration with ERN Guard-Heart, we at the Heart Rhythm Management Centre (HRMC) and Centre for Medical Genetics (CMG) of the University Hospital of Brussels, UZ Brussel, would like you to help us detect and monitor problems counselees experience within the cardio-genetic counseling process.

We are given the task to work out Patient Related Outcome Measures and Patient Related Experience Measures in the social-care path within cardiology and genetics. We would like to tackle the unmet needs of the counselee related to the clinical and genetic diagnosis, treatment and rehabilitation. We want to assess what the specific psychosocial issues' individuals encounter while undergoing (genetic) counseling for inherited cardiovascular disease.

A first step in this process would be to make an inventory of the health care work flow and questionnaires that are currently used in cardiology/ genetic departments throughout Europe to measure the psychosocial needs of patients.

Subsequently in October 2020, we would like invite you at the UZ Brussel (if possible by that time, following the COVID-19 regulations) for a meeting (or through live-streaming) with all stakeholders that have a major role in the healthcare value chain. The workshop is specifically oriented towards the clinical psychologist, healthcare workers, social nurses that work in a multidisciplinary cardiology/genetics center.

The purpose of this meeting would be to work out a guideline that will aid patients' decisional process in clinical and genetic testing, treatment and rehabilitation for inherited cardiovascular diseases. Our aim is to write an article with all participants on these more cardiac-specific and genetic-specific guidelines. In line with the strategy of developing condition-specific questionnaire modules to complement more generic quality of life measures.

We would like the psychologist, genetic counsellor or healthcare worker within your center, to fill in the online query.

Copy paste the URL in your web browser

https://vubdochumansciences.eu.qualtrics.com/jfe/form/SV_bKrTJ0yYOb8KDxr

By doing this the questionnaire will open. You can start and stop the questionnaire at a time convenient to you, the online platform will save your answers automatically.

If you have any question or encounter some difficulties in answering the questions, do not hesitate to contact me via saartje.vanpottelberghe@uzbrussel.be.

I hope to hear from you in the nearby future.

Greetings,

Sarah Van Pottelberghe

On behalf of the UZ Brussel ERN-GUARD HEART team ♥

**Please complete the
questionnaire before
15 august 2020**



ERN Board meeting

Tuesday, 1 September 2020

The next ERN GUARD-Heart Board meeting was originally planned during the ESC Congress in September in Amsterdam. As expected, the ESC Congress has been canceled due to the COVID_19 pandemic. However, we still aim to organize the Board meeting at **1 September 2020** (the original planned date). The meeting will be held online. The agenda and invitation-link will be sent in an e-mail as soon as possible. ♥

Latest ERN GUARD-Heart Publications

1. Lahrouchi N, Tadros R, Crotti L, Mizusawa Y, Postema PG, Beekman L, Walsh R, Hasegawa K, Barc J, Ernsting M, Turkowski KL, Mazzanti A, Beckmann BM, Shimamoto K, Diamant UB, Wijeyeratne YD, Kucho Y, Robyns T, Ishikawa T, Arbelo E, Christiansen M, Winbo A, Jabbari R, Lubitz SA, Steinfurt J, Rudic B, Loeys B, Shoemaker MB, Weeke PE, Pfeiffer R, Davies B, Andorin A, Hofman N, Dagradi F, Pedrazzini M, Tester DJ, Bos JM, Sarquella-Brugada G, Campuzano Ó, Platonov PG, Stallmeyer B, Zumhagen S, Nannenber EA, Veldink JH, van den Berg LH, Al-Chalabi A, Shaw CE, Shaw PJ, Morrison KE, Andersen PM, Müller-Nurasyid M, Cusi D, Barlassina C, Galan P, Lathrop M, Munter M, Werge T, Ribasés M, Aung T, Khor CC, Ozaki M, Lichtner P, Meitinger T, van Tintelen JP, Hoedemaekers Y, Denjoy I, Leenhardt A, Napolitano C, Shimizu W, Schott JJ, Gourraud JB, Makiyama T, Ohno S, Itoh H, Krahn AD, Antzelevitch C, Roden DM, Saenen J, Borggreffe M, Odening KE, Ellinor PT, Tfelt-Hansen J, Skinner JR, van den Berg MP, Olesen MS, Brugada J, Brugada R, Makita N, Breckpot J, Yoshinaga M, Behr ER, Rydberg A, Aiba T, Käab S, Priori SG, Guicheney P, Tan HL, Newton-Cheh C, Ackerman MJ, Schwartz PJ, Schulze-Bahr E, Probst V, Horie M, Wilde AA, Tanck MWT, Bezzina CR Transethnic Genome-Wide Association Study Provides Insights in the Genetic Architecture and Heritability of Long QT Syndrome. *Circulation*. 2020 May 20. doi: 10.1161/CIRCULATIONAHA.120.045956. Online ahead of print. *Circulation*. 2020. PMID: 32429735.

2. Makarawate P, Glinge C, Khongphatthanayothin A, Walsh R, Mauleekoonphairoj J, Amnueypol M, Prechawat S, Wongcharoen W, Krittayaphong R, Anannab A, Lichtner P, Meitinger T, Tjong FVY, Lieve KVV, Amin AS, Sahasatas D, Ngarmukos T, Wichadakul D, Payungporn S, Sutjaporn B, Wandee P, Poovorawan Y, Tfelt-Hansen J, Tanck MWT, Tadros R, Wilde AAM, Bezzina CR, Veerakul G, Nademanee K. Common and rare susceptibility genetic variants predisposing to Brugada Syndrome in Thailand. *Heart Rhythm*. 2020 Jun 30:S1547-5271(20)30626-3. doi:10.1016/j.hrthm.2020.06.027. PMID: 32619740.

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