

Tuesday 22 August 2023



GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart



ERN GUARD-HEART BIMONTHLY NEWSLETTER

YEAR 2023 NUMBER 5

Cancelation of the ERN Call

Amsterdam, 01-08-2023

Due to legal problems the European Commission faces with all Ukraine related activities, European Health & Digital Executive Agency (HADEA) has stopped the evaluation of the 24 submitted ERN applications and the call for grants has been cancelled. It is expected that a new will be launched. New ERN applications have to be resubmitted with an extra work package containing Ukraine-related activities (implying that all other work packages should be without Ukraine related activities). For ERN GUARD-Heart this entails that an extra work package has to be included in our application with Ukraine-related activities (besides the activities which were already described in the former application). To be able to create the necessary, important, but also enriching activities, we would like to ask input from our members and affiliated partners. Therefore we decided to add this as an extra topic to the agenda of the next board meeting on Monday 28 August. If you are not able to join the board meeting, please send us your ideas and thoughts regarding this topic by e-mail. The revised applications have to be submitted not later that September 19th. ♥

Amendment Bridging Grant

Amsterdam, 01-08-2023

The current ERN (bridging) grant will be extended by one month. This will be done through an Amendment, which will be initiated by HADEA. The end of the current ERN GUARD-Heart grant will be 30 September 2023. All usual costs will be eligible during this month of extension. ♥

ERN GUARD-Heart board meeting in Amsterdam

Amsterdam, 15-08-2023

This hybrid meeting will be held at **Monday 28th of August**, in the Rosarium, Amstelpark 1, in Amsterdam, which is on a 15 minutes walking distance (1,2 km) from the ESC (Amsterdam RAI) and a nearby train station to the airport. For all on site participants who subscribed, there will be lunch available from 12:15 PM, and the meeting will start at 13:00 (closure around 17:00). We are happy to announce that we expect 40 participants on site and almost 20 online. Please, let us know in time (as soon as possible), if there are unexpected changes in your schedules. Following the news of the cancelation of the next grant, we had to make a change in the agenda for the board-meeting. The updated agenda is attached separately for all our full-members and affiliated partners. Please, help us with interesting ideas for Ukraine-related ERN activities. See also the dedicated website: <https://www.erncare4ua.com> ♥





CPMS Helpdesk

Amsterdam, 01-08-2023

'My name is Malou van den Boogaard and I am working as a cardiologist in the Amsterdam University Medical Center. Ever since my PhD on molecular genetics in arrhythmogenesis, I have been enthusiastic about this topic and am therefore very happy to have my fellowship in Cardiogenetics here in June. In this context I will join the ERN team and I am available for questions on CPMS projects, but can also help with troubleshooting on that matter.'

Malou can be contacted directly by the following e-mail address:

cpmshelpdesk@guardheart.ern-net.eu ♥



Latest ERN GUARD-Heart Publication(s)

1. Crotti L, Spazzolini C, Nyegaard M, Overgaard MT, Kotta MC, Dagradi F, Sala L, Aiba T, Ayers MD, Baban A, Barc J, Beach CM, Behr ER, Bos JM, Cerrone M, Covi P, Cuneo B, Denjoy I, Donner B, Elbert A, Eliasson H, Etheridge SP, Fukuyama M, Girolami F, Hamilton R, Horie M, Iascone M, Jaimez JJ, Jensen HK, Kannankeril PJ, Kaski JP, Makita N, Muñoz-Esparza C, Odland HH, Ohno S, Papagiannis J, Porretta AP, Prandstetter C, Probst V, Robyns T, Rosenthal E, Rosés-Noguer F, Sekarski N, Singh A, Spentzou G, Stute F, Tfelt-Hansen J, Till J, Tobert KE, Vinocur JM, Webster G, Wilde AAM, Wolf CM, Ackerman MJ, Schwartz PJ. Clinical presentation of calmodulin mutations: the International Calmodulinopathy Registry. *Eur Heart J*. 2023 Aug 2:ehad418. doi: 10.1093/eurheartj/ehad418. Epub ahead of print. PMID: 37528649.
2. Neumann B, Vink AS, Hermans BJM, Lieve KVV, Cömert D, Beckmann BM, Clur SB, Blom NA, Delhaas T, Wilde AAM, Kääh S, Postema PG, Sinner MF. Manual versus Automatic Assessment of the QT-Interval and QTc. *Europace*. 2023 Jul 20:euad213. doi: 10.1093/europace/euad213. Epub ahead of print. PMID: 37470430.
3. Parisi V, Baldassarre R, Ferrara V, Ditaranto R, Barlocco F, Lillo R, Re F, Marchi G, Chiti C, Di Nicola F, Catalano C, Barile L, Schiavo MA, Ponziani A, Satri G, Caponetti AG, Berardini A, Graziosi M, Pasquale F, Salamon I, Ferracin M, Nardi E, Capelli I, Girelli D, Gimeno Blanes JR, Biffi M, Galiè N, Olivotto I, Graziani F, Biagini E. Electrocardiogram analysis in Anderson-Fabry disease: a valuable tool for progressive phenotypic expression tracking. *Front Cardiovasc Med*. 2023 Jun 21;10:1184361. doi: 10.3389/fcvm.2023.1184361. PMID: 37416917; PMCID: PMC10320218.
4. Bergeman AT, Robyns T, Amin AS, Wilde AAM, van der Werf C. Importance of exercise stress testing in evaluation of unexplained cardiac arrest survivor. *Neth Heart J*. 2023 Jun 22. doi: 10.1007/s12471-023-01789-w. Epub ahead of print. PMID: 37347419.

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