

Monday 4 October 2021

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

Share. Care. Cure.

ERN

GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart



ERN GUARD-HEART BIMONTHLY NEWSLETTER

YEAR 2021 NUMBER 5

ERN monitoring first semester 2021

Amsterdam, 22 September 2021



For ERN monitoring, we have to collect and submit our activities for the first 6 months of 2021. All members and affiliated partners have received a request by e-mail to deliver their activities and the number of NEW patients before 24 October 2021. These indicators are important for the evaluation of the ERNs and the continuation of the project after the first 5 year (i.e. at the end of February 2021). Please provide your files in time. In case of questions, contact us by sending an e-mail to Nynke Hofman (n.hofman@amsterdamumc.nl). ♥

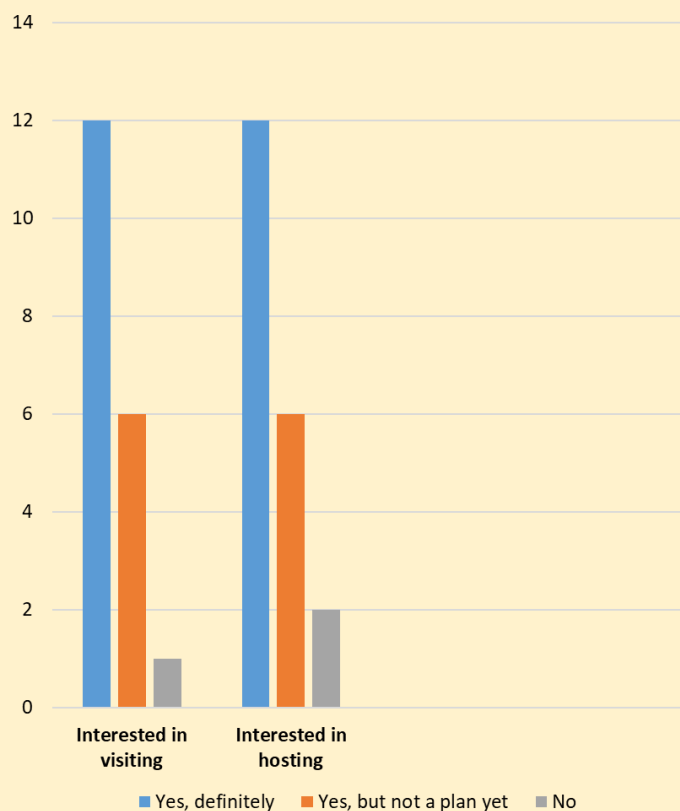
Survey for exchange possibilities



Amsterdam, 23 September 2021

To explore the possibilities and wishes for hosting and visiting other centres (full members and affiliated partners), we have created a short survey, as discussed at the board meeting of 15 September and requested by e-mail. The goal of the exchange programme is to stimulate collaboration between healthcare professionals in ERNs and sharing knowledge. All members of multidisciplinary teams can make use of the programme. **Thank you to those who already responded (19/32) and a kind reminder to those who did not yet (it takes only 1 minute):** <https://nl.surveymonkey.com/r/HJ5Q2ZQ> ♥

Preliminary survey results



Until now we received 19/32 replies to the Exchange-survey. Almost everyone seems to be interested in this nice opportunity to share knowledge. The next step is to put the plans into practice! We will send the necessary forms to those who indicated to have interest.





Patient Activities

**LMNAcardiac.org**

LMNA related heart disease?



Please join us at
lmnacardiac.org to take part in
our network of patients and
specialists

Foundation for LMNA-related Cardiac Diseases

Amsterdam, 25 September 2021

LMNA-related heart disease?

Please visit this group at lmnacardiac.org to take part in their network of patients and specialists.

LMNAcardiac.org is a network for LMNA-related cardiac diseases. The foundation has been setup recently by two patients with the idea to speed up research and development by connecting patients and experts with each other.

This great initiative is looking for more patients and professionals to build an even stronger network. For more information and/or to join the network see: <https://LMNAcardiac.org>. ❤

Publication from Eurordis and ERNs ePAG groups

USA, 26 September 2021

The EURORDIS and ePAG groups have written the article 'A preliminary set of measures to evaluate patient engagement in the European Reference Networks' which now has been published in Rare Disease and Orphan Drugs Journal. Simone Lousse, from our ePAG group contributed, and we would like to congratulate her and the other authors with this great achievement. Please find the direct link here: <https://rdodjournal.com/article/view/4266> ❤



Meeting for Brugada Syndrome patients

Amsterdam, 21 September 2021

On Tuesday 21 September, there was an online meeting for patients with Brugada syndrome in Belgium and the Netherlands (Dutch language), which was organized by HCPs from Leuven and Amsterdam. A PDF of the presentations is available on the ERN website, and there is also a (Dutch) summary of the questions and answers session. (<https://guardheart.ern-net.eu/patients/topic-meetings/meeting-brugada-syndrome/>) With about 160 online participants (and more than 200 subscriptions) we can conclude that there is really a need to organize these patient meetings. Please, realize, as announced before that there is financial support possible from the ERN, for full members and affiliated partners, to organize such meetings. Please contact the project-management for the options. ❤



Online Board meeting

Amsterdam, 15 September 2021

The 10th Board meeting from ERN GUARD-Heart was held (online) on 15 September. Thanks to all the 39 participants for their attention (some without video). Hopefully we are able to organize a physical meeting again in the beginning of 2022. ❤



X Jornada de Cardiogenética

Viernes 26 de noviembre 2021, 15:00 horas



Echa un vistazo al programa aquí:

Inscripción gratuita en:
jornadacardiogenetica.com/#inscripciones

Síguenos en Twitter: CardiopatiasH



Juan Gimeno, our full-member from the University Hospital 'Virgen de la Arrixaca', Murcia, Spain, is organizing the 10th edition of Jornada de Cardiogenética in Spain. It's a large meeting for patients and professionals, mainly online, but with 4 onsite workshops for professionals and patients. The final program is accessible via the QR-code on the flyer aside. Registration is free and it will be open by the 10th of October. ❤



ERN Transversal Working Group on Pregnancy and Family Planning – survey for clinicians

Pisa, 28 September 2021

The ERN Transversal Working Group on Pregnancy and Family Planning, represented by Giuseppe Limongelli and Ruth Biller from ERN GUARD-Heart, provided us with an update on the surveys that is being developed by the Working Group. Volunteers are finalising the translations of the patients' survey in the different languages, which is expected to be finished mid October. The survey for clinicians is ready to be completed here: https://ec.europa.eu/eusurvey/runner/ERN_PregnancyFamilyPlanning_HCPs ♥

Latest ERN GUARD-Heart Publications

1. Kallas D, Roston TM, Franciosi S, Brett L, Lieve KVV, Kwok S-Y, Kannankeril, PJ, Krahn AD, LaPage MJ, Etheridge S, Hill A, Johnsrude C, Perry J, Knight L, Fischbach P, Balaji S, Tisma-Dupanovic S, Law I, Atallah J, Backhoff D, Kamp A, Kubus P, Kean A, Aziz PF, Kovach J, Lau Y, Kron J, Clur S-A, Sarquella-Brugada G, Wilde AAM, Sanatani S. An Evaluation of Age at Symptom-Onset, Proband Status and Sex as Predictors of Disease Severity in Pediatric Catecholaminergic Polymorphic Ventricular Tachycardia, Heart Rhythm (2021), doi: <https://doi.org/10.1016/j.hrthm.2021.07.061>.
2. Marinello D, Galetti I, Dan D, Andersson AS, Aguilera S, Louisse S, Wiehe L, Aslanian AL, Martin IH. Patient engagement in healthcare: a preliminary set of measures to evaluate patient engagement in the European Reference Networks. Rare Dis Orphan Drugs J 2021;1:2. <http://dx.doi.org/10.20517/rdodj.2021.001>
3. Behr ER, Scrocco C, Wilde AAM, Marijon E, Crotti L, Iliodromitis KE, Remme CA, Kosiuk J, Rudaka I, Brugada GS, Frampton K, Schulze-Bahr E, Jubele K, de Asmundis C, Hofman N, Tfelt-Hansen J, Boveda S, Conte G. Investigation on Sudden Unexpected Death in the Young (SUDY) in Europe: results of the European Heart Rhythm Association Survey. Europace. 2021 Aug 5:euab176. doi:10.1093/europace/euab176. Epub ahead of print. PMID: 34351417.
4. Restrepo-Cordoba MA, Wahbi K, Florian AR, Jiménez-Jáimez J, Politano L, Arad M, Climent-Paya V, Garcia-Alvarez A, Hansen RB, Larrañaga-Moreira JM, Kubanek M, Lopes LR, Ros A, Jurcut R, Rasmussen TB, Ruiz-Guerrero L, Pribe-Wolferts R, Palomino-Doza J, Bilinska Z, Rodríguez-Palomares JF, Van Loon RLE, Basurte Elorz MT, Quarta G, Robledo Iñárritu M, Verdonschot JAJ, Stojkovic T, Shomanova Z, Bermudez-Jimenez F, Palladino A, Freimark D, García-Álvarez MI, Jorda P, Dominguez F, Ochoa JP, Girolami F, Brugada R, Meder B, Barriales-Villa R, Mogensen J, Laforêt P, Yilmaz A, Elliott P, Garcia-Pavia P; European Genetic Cardiomyopathies Initiative Investigators (see online supplementary Appendix S1). Prevalence and clinical outcomes of dystrophin-associated dilated cardiomyopathy without severe skeletal myopathy. Eur J Heart Fail. 2021 Aug;23(8):1276-1286. doi: 10.1002/ehf.2250. Epub 2021 Jun 9. PMID: 34050592
5. Verstraelen TE, van Lint FHM, Bosman LP, de Brouwer R, Proost VM, Abeln BGS, Taha K, Zwinderman AH, Dickhoff C, Oomen T, Schoonderwoerd BA, Kimman GP, Houweling AC, Gimeno-Blanes JR, Asselbergs FW, van der Zwaag PA, de Boer RA, van den Berg MP, van Tintelen JP, Wilde AAM. Prediction of ventricular arrhythmia in phospholamban p.Arg14del mutation carriers-reaching the frontiers of individual risk prediction. Eur Heart J. 2021 Jul 31;42(29):2842-2850. doi: 10.1093/eurheartj/ehab294. PMID: 34113975; PMCID: PMC8325776.

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