

Wednesday 7 May 2025

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



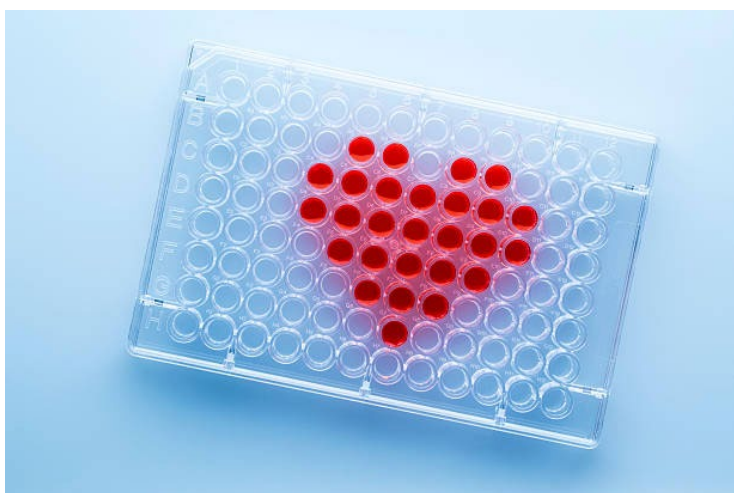
ERN GUARD-HEART BIMONTHLY NEWSLETTER

YEAR 2025 NUMBER 1

Last call for ERN budget for patient meetings until 1 October 2025

Amsterdam, 2 May 2025

With May already underway, it's time to start planning potential patient meetings for the second year of the current grant period, which runs until October 1. Each country has an allocated budget for organizing patient meetings. Some countries have already held one or more meetings, while others have yet to do so. We kindly encourage you to organize a meeting for your patients, using the ERN budget. This budget can be used, for example, to cover venue rental, refreshments or lunch, or patient travel expenses. Please contact the coordination office to find out the available national budget, share your draft plans, and submit your request. We also encourage you to collaborate with your national patient advocacy groups. (contact: n.hofman@amsterdamumc.nl). ♥



Successful ERN exchange programme, some packages left

Amsterdam, 2 May 2025

The ERN Exchange Program has been designed to facilitate knowledge sharing within the ERNs, including ERN GUARD-Heart, and to foster collaboration among healthcare professionals across different ERNs. Since October 2024, several successful visits have already taken place in ERN GUARD-Heart, and there are exchange packages still available.

As a reminder, here are some key details: the Program is open to both full members and affiliated partners. Funded by the ERN (in line with unit cost rules), it allows for a five-day visit to a hosting center. Each healthcare provider (HCP) can submit a maximum of one application as a visitor per year. Requests for longer visits may be considered, depending on the number of applications received. A total of 15 five-day packages are available annually.

Once you have identified a hosting hospital, you can apply for an exchange package by completing the 'mobility agreement,' outlining your objectives, planned activities, and expected outcomes. This form is available on the website of the ERN and must be signed by the visiting center, the hosting center, and the ERN coordinator.

Plans for visits taking place before 1 October 2025 should be submitted by 1 June. If you have any questions, please contact the ERN coordination office. ♥



Who are our ePAGs?

Florence, 1 May 2025

One of the European patient advocates of ERN GUARD-Heart in the spotlight: *Matteo and Annalisa* are co-founders of AICARM, the Italian Cardiomyopathy association. They tell their story.

The Italian Association of Cardiomyopathies (AICARM) is a dedicated organization comprising patients and healthcare professionals focused on enhancing the understanding, diagnosis, and treatment of cardiomyopathies in Italy. Established to bridge the knowledge gap surrounding these often underrecognized heart diseases, AICARM emphasizes patient support, education, and the dissemination of the latest medical advancements. Through initiatives like webinars, training sessions, and support services, the association strives to improve the quality of life for those affected by cardiomyopathies and their families. Since its inception in 2019, AICARM has been improving on all KPIs, as shown in the picture below.

In alignment with its mission to promote cardiovascular health and community awareness, AICARM has recently launched a significant initiative aimed at educating Milanese high school students in cardiopulmonary resuscitation (CPR) and the use of automated external defibrillators (AEDs).

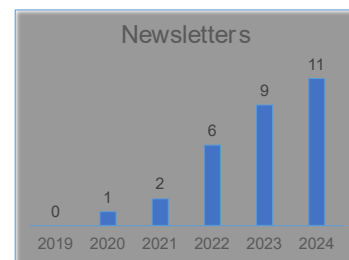
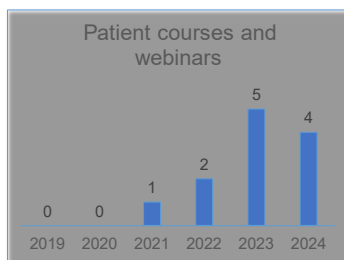
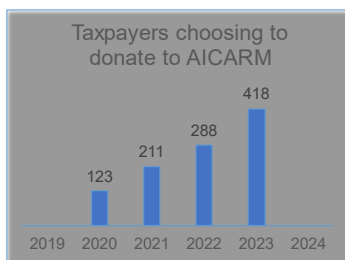
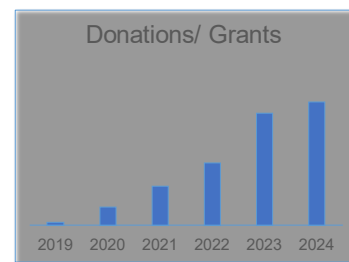
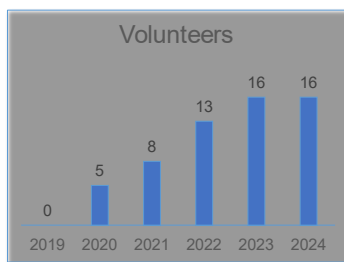
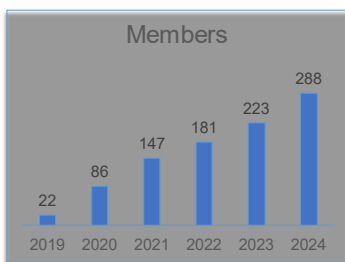


Matteo & Annalisa

This project, introduced in the 2024/2025 academic year, is a collaborative effort between AICARM, the Auxologico Institute of Milan (ERN GUARD-Heart hospital), and Fapy srl. It is designed to equip young individuals, aged 16 to 18, with essential life-saving skills, thereby fostering a community capable of responding effectively to cardiac emergencies. The initial idea about this project came from the “Cardioprotect your core” project of the Barcelona-based SAMS (Association for Patients and Relatives with Sudden Death-Related Arrhythmic Syndromes), also an ePAG for ERN GUARD-Heart, represented by Ester Costafreda.

-- See next page --

AICARM KPIs growing since inception





Who are our ePAGs?

Matteo Pincioli and Annalisa Gebbia (continued)

The training program adheres to the 2020 guidelines of the International Liaison Committee on Resuscitation (ILCOR) and is structured in two comprehensive phases. The initial phase encompasses theoretical instruction, enabling students to recognize the signs of cardiac arrest and understand the critical steps required during such emergencies. The subsequent phase offers practical, hands-on experience, where students engage in cardiac massage exercises using mannequins and practice AED operation. Upon completion, participants receive a certificate of attendance, which can be utilized to obtain educational credits, underscoring the program's academic and practical value.

The initiative has been well-received by educational institutions across Milan, with several high schools integrating the training into their curricula. The following schools have already hosted the CPR courses:

- Istituto Leone XIII: Course conducted on September 27, 2024.
- International School of Milan: Course conducted on December 5, 2024.
- Istituto Leopardi: Course conducted on December 5, 2024.
- Istituto Cardano: Course conducted on January 23, 2025.
- Liceo Stendhal: Course conducted on February 8, 2025.
- Liceo Berchet: Course conducted on February 10, 2025.
- Liceo Vittorini: Course conducted on March 13, 2025.

Educators have recognized the civic and educational significance of this program, allocating approximately three hours of classroom time to ensure students gain these vital skills. The overarching goal is to train around 10 classes, each comprising 20 to 25 students, thereby creating a ripple effect of preparedness and awareness throughout the community. This proactive approach by AICARM not only empowers students with the competence to act decisively during cardiac

emergencies but also aligns with national legislative efforts. The Italian law enacted on August 4, 2021, n. 116, advocates for the widespread availability and use of AEDs in public spaces, including educational institutions. It authorizes trained non-healthcare individuals to operate defibrillators, and in urgent situations, even those without specific training are permitted to use AEDs to ensure timely intervention.

Despite the enactment of this legislation, the integration of life-saving techniques into school curricula has been sluggish. As highlighted in a recent article by Corriere della Sera, the teaching of resuscitation maneuvers and defibrillation has yet to become a standard component of educational programs. In response, volunteer associations like AICARM have taken the initiative to fill this gap, providing essential training to students and ensuring that the community is better prepared to handle cardiac emergencies.

Through this initiative, AICARM exemplifies its commitment to fostering a cardio-protected community. By equipping the younger generation with essential life-saving skills, the association not only addresses immediate health concerns but also instills a culture of responsiveness and care that can have lasting impacts on public health and safety. ❤️



aicarm

ASSOCIAZIONE ITALIANA CARDIOMIOPATIE



ERN Board Meeting in the Netherlands

Maarsse, 14 March 2025

On Friday 14 March, the ERN Board members, affiliated partners and representatives from the European patient advocacy groups participated in the 17th ERN Board Meeting, which was organized in the former monastery of country estate 'Doornburgh' in Maarsse, the Netherlands. With 42 physical attendees, it was a good and interactive network meeting. Thanks to all the attendees for their active participation. ❤





Update on the status of full members in ERN GUARD-Heart

Maarsse, 14 March 2025

One of the full members of ERN GUARD-Heart, ICS Mageri from Pavia, has decided to withdraw its membership from ERN GUARD-Heart. This decision was communicated via email by the main representative and former Thematic Area 1 leader, Carlo Napolitano. In accordance with official procedures, the board was informed of this decision during the board meeting and has approved it. The European Commission has also been notified.

We extend our sincere thanks to the team in Pavia for their valuable contributions to the ERN over the past nine years. We expect that scientific collaboration with many ERN centers will likely continue in the future. With this change, ERN GUARD-Heart now counts 43 full member centers.



Time consuming approval joint data registry agreement

Maarsse, 14 March 2025

The approval process for the Joint Data Registry Agreement (JDRA) by the data protection officers at Amsterdam UMC, intended for use in ERN registries on genetic cardiac diseases, has been slow. It is anticipated that obtaining final approval and securing signatures from each HCP will take considerable time. This delay poses a significant barrier to establishing new registries and prevents centers from enrolling patients in both existing and future registries. To address this challenge, the network board proposes the creation of an action group dedicated to developing the legal and administrative framework needed to support the successful implementation of registries within the ERN. Consequently, the registry budget will be allocated - at least in part - to support the activities of this action group. ❤



Latest ERN GUARD-Heart Publications

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2. Setti M, Iseppi M, Verdonschot JAJ, Rizzi JG, Paldino A, Pio Loco Detto Gava C, Barbati G, Dal Ferro M, Venner MFGHM, Raafs AG, Gigli M, Stolfo D, De Luca A, De Angelis G, Capovilla TM, Graw S, Ribichini FL, Taylor M, Mestroni L, Heymans SRB, Sinagra G, Merlo M. **Integrated role of cardiac magnetic resonance and genetics in predicting left ventricular reverse remodelling in dilated and non-dilated cardiomyopathy.** *Eur J Heart Fail.* 2025 Apr 29. doi: 10.1002/ehf.3671. Epub ahead of print. PMID: 40296583.
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Latest ERN GUARD-Heart Publications

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