

ECGen survey

14 December 2020



ECGen survey results



- Sent to 82 members
- 50 replies (38 shared their emails)
- Sent on 8 October with 4 reminders
- Deadline 22 October



Q2 Please indicate how important each area is to you and where you would most want ECGen to focus its efforts on. Please select by order of preference



Q3 Do you have specific suggestions or proposals?



| t | o work with EU Brussels to invest more on genetic research | | |
|---|--|--|--|
| | Develop European and International Research Networks involving ECGen members | | |
| | ranssectional research, education and training alongside with deliberate fostering of collaborations | | |
| I | am looking forward to attend research networks | | |
| F | Focus on education and research | | |
| | Vould like to see arrhythmogenic cardiomyopathy (considerable overlap cardiomyopathy/arrhythmic disorder) if the committee feel his is appropriate | | |
| | think the main goal of ECGen should be networking opportunities between people interested in cardiogenetics. This will automatically lead to developing guidelines/patient pathways/education/ foster collaboration | | |
| I | have not specific suggestion.Thank you. | | |
| | think it can be useful in some topics (ie. patientpathways, educational seminars) to work together with the patient advocates of the ERN. | | |
| E | 1) Training opportunities for junior doctors: courses/ESC certification on ICC management (including ECG/imaging/genetics). 2) Educational seminars on principles of genetics of ICC and variant interpretation ad ICC diagnosis/management. 3) Genetics focused ESC journal | | |
| r | ecommendations for treatment and follow-up in channelopaties | | |
| ٦ | raining programs, observeveship sabbatical | | |
| C | liscussion board on difficult cases | | |
| I | would be very interested in contributing to position statements and the development of research networks / research grants | | |
| | Development of practical educational products eg, Care pathway posters for clinic walls for patients with Inherited cardiac conditions | | |
| - | | | |



Q3 Do you have specific suggestions or proposals?



Answered: 50 Skipped: 0

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|---|-----|
| Develop a network and possible funding to support training fellowships in accredited centres across Europe | |
| also include translational seminars and webinars | |
| EHRA/ESC position/consensus paper pregnant with inherited cardiac diseases | |
| Education on genetics for cardiologists (and probably Education on cardioloy for geneticians | |
| Training grants | |
| Expanding and creation of international registries of rare genetic arrhythmic disorders | |
| Be part of ECgen community | |
| e-learning or in-person 4 day course on different subject or different level. Maybe obtain all the porposed ocurse will lead to a graduation/certification | 3 |
| education is most important | |
| Since ICC are relatively rare, it would be good to join forces to conduct multi-centre studies to increase sample sizes. | |
| not at the moment | |
| ECGen should build prospective validated registries with very specific inclusion, exclusion criteria and method of reporting of inherited arrhythmia syndrome | the |
| Webinars | |
| Training programs, observeveship sabbatical | |
| if we would focus on recommendations we should focus on the really rare ones, in roder to avoid overlap with existing guideli | nes |
| | |

