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| Please return the entire completed document, including the last section, “Acceptance” (page 5), to: [HFA@escardio.org](mailto:HFA@escardio.org) |

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Association, Council or Working Group involved (if more than one, please indicate all with the leading group listed first)

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| ESC entity |
| Heart Failure Association (HFA) |
| Select entity |
| Select entity |
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| Other entity |
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Tentative title

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| Living with peripartum cardiomyopathy (PPCM). A Statement of the Heart Failure Association (HFA) of the ESC. |

List of authors (please stratify by group) – See **ANNEX 1** of this proposal form for further instructions

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| Karen Sliwa (1), Amina Rakisheva, Maggie Simpson, Peter van der Meer (3), Mark C. Petrie (4), Alice Jackson (4), Hasan Al Farhan (5), Kai Kahl (6), Silvana Jovanova, Amam Mbakwem, Gianfranco Sinagra, Emeline Van Craenenbroeck, Giuseppe Rosano, …., Johann Bauersachs (7) 1. Cape Heart Institute, Faculty of Health Sciences, University of Cape Town, South Africa;  2. Scientific Institution of Cardiology and Internal Medicine Almaty, Kazakhstan.  Department of Cardiology, University Medical Center Groningen, The Netherlands;  4. Golden Jubilee National Hospital, Glasgow, United Kingdom;  5. Baghdad Teaching Hospitals-Medical City, Iraq. 6. Department of Psychiatry and Psychotherapy, Hannover Medical School, Hannover, Germany 7. Department of Angiology and Cardiology, Hannover Medical School, Hannover, Germany |

All authors will need to submit a Declarations of Interest (DOI) in the ESC DOI platform. This will be reviewed according to the ESC DOI policy and inclusion criteria for writing groups– See **ANNEX 2** of this proposal form for further information.

Justification, scope and objectives – See **ANNEX 3** for further instructions

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| This statement will be developed during/after a workshop to be held in May/June 2023. The aim of the interdisciplinary multiprofessional workshop is to prepare a scientific document on “Living with peripartum cardiomyopathy”.   Over the past years the medical community has recognized that the patient voice is fundamental to the medical decision making and adherence to medication. We have therefore decided to prepare a workshop addressing PPCM from the patient perspective which impacts the long-term management and compliance with this serious disease affecting women of child-bearing age and their relatives.  In addition to members of the HFA PPCM Committee and HFA Board, authors will include experts in obstetrics, psychology/psychiatry, intensivists and – if possible 1-2 women who have suffered from PPCM. Those women would take part in person or per zoom. Patient groups will be included with support from the ESC Patient Office.  We also plan to include results from a survey in the PPCM EORP registry “Social implications of PPCM diagnosis”. Our data (submitted to European Journal Heart Failure) have shown that poor patients education and poor access to health care have a greater impact on outcome than e.g. ethnicity.   Outline:  The diagnosis of PPCM puts a major threat to the patient, and (if still pregnant) also to the fetus.  Beyond the physical illness with acute heart failure up to cardiogenic shock and necessity of treatment on an intensive care unit, the psychologic and social stress is substantial, both during the acute phase but also thereafter. Especially the disease also impacts the partner and other family members who need to support the patient.   Recently, it has been shown in a German PPCM cohort that the majority of PPCM patients displayed mental disorders with a higher prevalence of major depressive disorders, post-traumatic stress disorder, and panic disorder, compared with healthy postpartum women.   If the patients is not critically ill, the question of breast-feeding is of major importance as well as the initiation and often long-term continuation of a multi-drug treatment regimen for heart failure. If the patient is critically ill, the implantation of short- and potentially long-term mechanical ventricular support as well as heart transplantation puts major threat to the patient and her relatives. A special threat to all PPCM patients is the question whether a subsequent pregnancy will be possible in the future.   Questions to be addressed:  - What do women with PPCM know about their condition (drafting of a survey)  - What are the data for long-term medical therapy and what is the patient’s perspective on life-long treatment with heart failure medication?  Actions needed: - Development of a survey  Increased awareness - Development of an educational 3-5 min video (in English) - Dedicated section on HFA patient website   Close monitoring and organization of psychosocial support - Getting input for self-help from psychologist  Organization of the self-management support provided by nurses at the primary care level - The input for self-management support from nurse practitioners  Central Figure : to be developed for the manuscript   Other related recent papers that will be cited in the planned scientific document: 1. Sliwa K, Bauersachs J, et al. Peripartum cardiomyopathy: from genetics to management..  Eur Heart J. 2021;42(32):3094-3102. doi: 10.1093/eurheartj/ehab458. 2. Sliwa K, van der Meer P, Petrie MC, et al..Risk stratification and management of women with cardiomyopathy/heart failure planning pregnancy or presenting during/after pregnancy: a position statement from the HFA of the ESC Study Group on PPCM. Eur J Heart Fail. 2021 (4):527-540. doi: 10.1002/ejhf.2133 3. Sliwa K, Petrie MC, van der Meer P, et al. Clinical presentation, management, and 6-month outcomes in women with peripartum cardiomyopathy: an ESC EORP registry. Eur Heart J. 2020; 41(39):3787-3797. doi: 10.1093/eurheartj/ehaa455. 4. ESC Guidelines on the “Management of cardiovascular diseases during pregnancy” Eur Heart J 2018. 5. Bauersachs J et al. Pathophysiology, diagnosis and management of peripartum cardiomyopathy. European Journal Heart Failure 2019 6. Seferovic P et al. Heart failure in cardiomyopathies. European Journal Heart Failure 2019 7. ESC Guidelines “Heart Failure” Eur Heart J 2021 8. Berliner D et al, Clinical characteristics and long-term outcomes in patients with peripartum cardiomyopathy (PPCM) receiving left ventricular assist devices (LVAD). Artif Organs. 2022. doi: 10.1111/aor.14406. 9. Pfeffer TJ, et al, Assessment of major mental disorders in a German peripartum cardiomyopathy cohort. ESC Heart Fail. 2020;7(6):4394-8. doi: 10.1002/ehf2.12967. |

Target Journal for Submission – See **ANNEX 4** for further instructions

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| European Journal of Heart Failure (EJHF) |
| Select ESC journal or enter text |
| Select ESC journal or enter text |
| Free Text Field (if needed) |

Planned submission date: 01/10/2023

Additional Comments

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| Please enter any additional comments you might have |

**BY RETURNING THIS COMPLETED DOCUMENT, YOU ALSO CONFIRM THAT YOU READ AND AGREED ON THE FOLLOWING TERMS ON BEHALF OF YOUR CO-AUTHORS:**

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| **ANNEX 1. ADHERENCE TO ICMJE AUTHORSHIP CRITERIA**  The Internal Committee for Medical Journal Editors (ICMJE) has set forth the following criteria for authorship:  *“The ICMJE recommends that authorship be based on the following 4 criteria:*   * *Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work;* ***AND*** * *Drafting the work or revising it critically for important intellectual content;* ***AND*** * *Final approval of the version to be published;* ***AND*** * *Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.*   *In addition to being accountable for the parts of the work he or she has done, an author should be able to identify which co-authors are responsible for specific other parts of the work. In addition, authors should have confidence in the integrity of the contributions of their co-authors.”*  Source: <http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html> |

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| **ANNEX 2. DECLARATIONS OF INTEREST**  it is the obligation of the Association, Council or Working Group to ensure that the Declarations of Interest of authors are reviewed according to ESC DOI Policy and criteria (see [Annex 3](https://www.escardio.org/static-file/Escardio/Web/Documents/Annex-3-rules-assessment-conflicts.pdf) of the [ESC Declaration and Management of Conflict of Interest Policy](https://www.escardio.org/The-ESC/About/Policies/esc-declaration-and-management-of-conflict-of-interest-policy)).  Outside periodic calls for, and review of declarations, experts involved in document writing should immediately report to the Lead Author and their Association, Council or Working Group leading the project any change in their relationship with industry that may impact their role in the project. |

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| **ANNEX 3. MANDATORY REVIEW BY THE ESC COMMITTEE FOR PRACTICE GUIDELINES (CPG)**  The ESC CPG must review and approve all Scientific Documents published on behalf of ESC Associations, Councils and Working Groups. Specifically, the CPG must review and approve:   1. The **proposal form** 2. The **final draft of the manuscript** before submission to the journal   Two major aspects are scrutinized by the CPG in this process:   1. That documents are consistent and avoid overlap with messages included in published or forthcoming ESC Guidelines. 2. As the scope and the development process for these documents differs from that of ESC Guidelines, that their presentation must not confuse readers in thinking that they may be official Clinical Practice Guidelines. For this reason, Scientific Document are to avoid any of the classic elements included in ESC Guidelines, such as:    1. Colour-coded tables/symbols as in, or close to ESC Guidelines’ tables    2. Classes of recommendations    3. Levels of evidence    4. Language similar to that used in ESC Guidelines (is recommended, should/may be considered, is not recommended)    5. The term “recommendation” in the title and within the text |

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| **ANNEX 4. TARGET JOURNAL**   1. Upon approval of the CPG, this Proposal Form will be shared with the editor of the selected ESC family journal. Any interest communicated by the editor **does not guarantee** final acceptance of the document for publication. 2. Please indicate if for the project is to be co-published, as this is important information to communicate to the journals and to coordinate a publication date. 3. When submitting the manuscript to an ESC Journal, **Authors must not select the Open Access option**. 4. In case the Scientific Document is not accepted for publication by one of the ESC Journals, it may be submitted to non-ESC journals as an independent, non-affiliated manuscript (not as an ESC Scientific Document, i.e. without reference to ESC Associations, Councils or Working Groups). |

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| **ACCEPTANCE**  On behalf of all authors involved with this scientific document, I confirm that I read, understood and will adhere to the ESC rules outlined in the Annex 1-4 of this form. |  |