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# WORKING GROUP ON RARE CANCERS

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## Terms of Reference

The Joint Action on Rare Cancers (JARC) and the European Reference Networks (ERN) are crucial game changers for rare cancer patients in Europe. These EU projects bring together scarce knowledge and fragmented resources, maximising synergies and results. The European Cancer Patient Coalition (ECPC) is honoured to contribute and to be one of the organisations that is representing the unmet needs, rights and hopes of rare cancer patients in the JARC, especially since rare cancers have been a priority for ECPC since its creation.

ECPC will build on its work conducted during the last three years on the [RARECAREnet](#) project. To continue to represent the rare cancer patient community, ECPC counts on the expertise and collaboration of rare cancer patient organisations all over Europe.

Following the formal request of several rare cancer patient representatives during the [ECPC AGM 2016](#), ECPC established a Working Group on Rare Cancers (WGRC), working in parallel with the JARC, to guarantee that a large number of rare cancer patient organisations, representing different European countries and rare cancer types, will be able to contribute to the activities of the JARC.

## Working Group Membership

WGRC Members are ECPC Members (Full and Associate) and non-member organisations with an interest in rare cancers.

## Objectives

WGRC representatives provide the patient perspective on the Joint Action on the Rare Cancers and discuss on any topic relevant to rare cancers. Specifically, representatives should:

- Contribute to the JARC activities, providing feedback and advice on all relevant tasks;
- Ensure that patient concerns are appropriately addressed within the JARC;
- Contribute to the development of patient information, rare cancer policies, quality standards for rare cancers, best clinical practices and recommendations;
- Contribute to the dissemination of patient information on rare cancers both at national and European levels;
- Provide the patient perspective on the unmet needs of people living with rare cancers in their country;
- Share with ECPC any other topic related to rare cancers;

- Contribute to the increase of the WGRC membership in order to establish networks of rare cancer organisations in all countries for a better connection with the Member States and for a better support to rare cancer patients.

### Meetings and communication

The WGRC will meet at least once a year, including at a session during the ECPC AGM. ECPC will invite JARC coordinators and partners to attend one of the meetings upon availability. The WGRC will also meet at several times a year via teleconference. The group will communicate mainly by email. ECPC will also look for further means of communication for the WGRC such as the creation of an online platform.

All members of the WGRC will be invited to attend the European Conference on Rare Cancers at the end of the Joint Action.

### Working Modalities

- These terms of reference cover a period equal to the duration of the JARC. Should the working group be deemed necessary after that date, it will be revised with the members and the ECPC Board.
- The ECPC Secretariat will coordinate the activities of the WGRC
- The recommendations submitted to the JARC on behalf of the WGRC will be based on a clear consensus of the members' views expressed during face-to-face meetings and on the online platform.
- The tools provided by ECPC will include a voting system for WGRC members to vote on proposals for recommendations.
- There is no limit to the number of members of the WGRC, and all rare cancer patient organisations are invited to participate.
- A list of rare cancer patient organisations who are members of the WGRC will be available on the ECPC website.

### Chairs of the Working Group

Jana Pelouchova, ECPC Secretary, is a rare cancer patient (CML) and will be the Chair of the WGRC. The WGRC will vote for two elected members to be vice-chairs of the WGRC

The Chair and vice-chairs of the Working Group will be responsible for:

- Defining the agendas of future WGRC meetings
- Overseeing the implementation of the work to be done
- Moderating and involving everyone in the discussions
- Guiding the work of the WGRC and defining its priorities
- Representing the WGRC in JARC meetings or other relevant meetings

The Chairs may also propose a new task to be carried out by the WGRC with the help of the ECPC Office.

Communication among the Chairs will be carried out through emails and teleconferences.

The vice-chairs are appointed for a one-year term renewable by agreement for a further one-year period. There is no remuneration for this role.

### Logistics

Administrative support for the WGRC meetings will be provided by the ECPC. Namely:

- Travel arrangements
- Accommodation
- Organisation of teleconferences
- Sharing of information and news
- Links to the JARC coordinators