



# RITA Patient Advocacy Group (RIPAG)

## Terms of Reference

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*'Patients and patient representatives should play an integral role in the decision and opinion making process in RD ERNs and be involved in structural and clinical network activities'.<sup>1</sup>*

*'Ensuring that the network has a patient-centred approach is a key objective'.<sup>2</sup>*

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<sup>1</sup> Rare Disease European Reference Networks: Addendum to EUCERD recommendations of January 2013

<sup>2</sup> RITA Work plan 2017

## BACKGROUND

### European Reference Networks

European Reference Networks (ERNs) are virtual networks involving healthcare providers across Europe. They aim to tackle complex or rare diseases and conditions that require highly specialised treatment and concentrated knowledge and resources.<sup>3</sup>

### RITA

RITA is the European Reference Network for Rare primary immunodeficiencies, autoinflammatory, autoimmune diseases and paediatric rheumatology<sup>4</sup>.

### European Patient Advocacy Groups (ePAG)

The European Organisation for Rare Diseases – EURORDIS - initiated a European Patient Advocacy Group (ePAG) for each ERN. European Patient Advocacy Groups (ePAGs) bring together rare disease patient advocates who are actively involved in the work of the European Reference Networks. Each ePAG corresponds to the scope of one of the 24 ERNs, aligning patient organisations and clinicians, experts and researchers working on the same rare or complex disease or highly specialised intervention.

### RIPAG

RIPAG (RITA Patient Advocacy Groups) represents the Patient Community for the European Reference Network (ERN) RITA.

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## MISSION

To safeguard the patient centric profile of the RITA ERN and contribute to the RITA network according to the critical roles patient and patient representations play, as experts by experience and co-producers of knowledge in all ERN activities.

## GOALS

To be a high value partner in the RITA network respected by all RITA Health Care Providers.

To play an active role in the RITA network by participating in each of the RITA Workgroups in order to make sure patient involvement is provided in all these areas.

## OBJECTIVES

In order to achieve its goals and mission RIPAG has set the following objectives:

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<sup>3</sup> [https://ec.europa.eu/health/ern/policy\\_en](https://ec.europa.eu/health/ern/policy_en)

<sup>4</sup> [www.riet.ern-net.eu](http://www.riet.ern-net.eu)

- Represent the voices and needs of rare disease patients in the activities of the ERN and in related initiatives;
- Contribute to the development of patient information, treatment policies, good practice guidelines and care pathways;
- Support the network with the dissemination of information and communication to the wider patient community;
- Contribute to the development of research priorities and ensure they are informed of the needs of patients and their families;
- Advise on ethical issues on the application of personal data rules, compliance of information consent and management of complaints;
- Engage with the appropriate patient communities for disease specific activities and projects.

## ORGANISATION

Bottom-up the RIPAG organization is structured as follows:

- RIPAG Members:  
Patient Advocacy Groups and organisations dealing with primary immunodeficiencies, autoinflammatory, autoimmune diseases and paediatric rheumatology.
- RIPAG Council:  
The collection of RIPAG Representatives with an official mandate to represent their Patient Advocacy Group and who are actively participating in RITA and/or RIPAG Working Parties.  
The RIPAG Council members may ask for specific ad hoc tasks related to RITA for the participation of specific RIPAG members.
- RIPAG Board:  
A group of RIPAG Council members elected by the RIPAG council and representing RIPAG in the RITA executive board.

## RIPAG Members

RIPAG Members are passive Patient Organisations that have registered with EURORDIS to be engaged with the ERN RITA and RIPAG to:

- collaborate on specific tasks (e.g. respond to surveys),
- disseminate information about the ERN across their wider patient community,
- be consulted occasionally for feedback, and
- be kept informed on the development of the ERN and of the RIPAG.

Only Patient Organizations meeting all of the following requirements can apply to join RIPAG:

- Represents a disease that belongs to the scope of ERN RITA diseases.
- Acts in the interests of a relevant specific rare disease community.
- Is registered and operating within Europe.

Any exception to the above criteria will have to be unanimously approved by the RIPAG Board.

To become a RIPAG Member, a Patient Organisation should contact the EURORDIS ERN team or register via the **online registration portal**. The organisation should indicate that it wishes to be informed of the RITA & RIPAG work. The patient organisation is to identify and provide the name of a contact person who will be the liaison between the Patient Organisation and RIPAG. The EURORDIS ERN team will inform RIPAG of any Patient Organisations interested in becoming members.

## **RIPAG Representatives**

RIPAG Representatives are individuals who have an official permanent mandate to represent their RIPAG Member organisation. They liaise between their organisation and RIPAG to ensure true and equitable representation of the patient voice in RITA and to guarantee proper feedback from RITA to their organization.

RIPAG Representatives are committed to be involved in the network activities and they are active in the ERN governance structure including its work streams and working groups<sup>5</sup>. RIPAG Representatives collaborate with the RITA clinicians and the research leads on a set of different activities such as the development of patient information, treatment policies, good practice guidelines, care pathways, research priority setting, etc.

RIPAG Representatives also commit to adhere to the following core values:

- respecting the mission of the RITA Board and its governance structure,
- listening to the opinions and requests of others,
- showing solidarity, mutual respect and support,
- adhering to the principles of equality and social justice,
- conducting themselves with professionalism and in accordance with the Code of Conduct & Ethics,
- having the capacity to be active in RITA and report regularly on their activities<sup>6</sup>,
- to represent not only your own arm, but also the other arms within RITA (especially in the WGs), to represent the whole community of rare and complex diseases following the scope of RITA,
- to represent their disease or disease area when needed,
- to actively participate and regularly attend RIPAG Council/Board meetings in person<sup>7</sup>. This may not be deputised on a regular basis.
  - Participation at the meetings will be monitored according to the ePAG Impact Assessment Framework.

The eligibility criteria for RIPAG Representatives are:

- To be officially endorsed by one or more Patient Organisation and/or Patient Group;
- To be experienced in living with the rare disease included under the scope of the ERN or hold relevant expertise corresponding to the scope of the ERN Transversal Working Groups;
- To agree to adhere to the set of core values mentioned above;
- Be fluent in English (written and spoken).

Any exception to the above criteria will have to be unanimously approved by the RIPAG Board.

Individuals who want to become a RIPAG Representative have to express their interest to the EURORDIS ERN team by providing all of the following:

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<sup>5</sup>More information on the work streams and working groups can be found on the RITA website.

<sup>6</sup>The EURORDIS ePAG Constitution states that "Patient representative involvement in an ERN is an important and unique opportunity to achieve a step-change in care for rare disease patients in Europe. Active involvement in an ERN requires a considerable investment in terms of time and workload for ePAG Patient Advocates in order to achieve meaningful benefits for our community. ePAG Patient Advocates are required to commit time to their role and is estimated as at a **minimum two days per month**. There will be patient advocates whose workload will be even bigger. It is recognised that for the ePAG Community, it can be from time to time impossible to meet this level of commitment and every effort will be made to support patient representatives where necessary".

<sup>7</sup>RIPAG Council/Board members are expected to attend a minimum of 75% of meetings. Monitoring will take place and if over a 12-month period this is not achieved, their mandate will be withdrawn, and the member will be demoted to a RIPAG member (i.e. removed from the Council/Board).

- a short biography,
  - a recommendation letter from their organisation,
  - a copy of the patient organization registration document,
  - a \*conflict-of-interest statement,
    - The independence of the RIPAG Representatives should always be a priority, especially with regards to scientific and professional societies. Membership to any society should be stated in the conflict of interest form, indicating any participation to any Board or decision-making body of the society.
  - a \*non-disclosure agreement (NDA).
- \* A standard, approved template will be provided for candidates to sign.

EURORDIS will validate the request (based on a review of the documents provided by the candidate) and advise the RIPAG Board accordingly. **Failure to meet ALL of the requirements is an automatic decline with no exceptions.**

All candidates who meet the requirements must still be put before the RIPAG Board, who will then accept or decline the request and agree on the level of involvement of the candidates.

A Patient Representative appointment in RITA comes to an end if:

- the RIPAG Patient Representative sends a notice of resignation to the RIPAG Board,
- the Patient Organisation can recommend a new individual to represent their organisation in RIPAG. The process will start from the beginning and the candidate will have to be voted on by the RIPAG Board.
- the RIPAG Board decides that it is in the best interests of RITA that the representative in question should be removed.
- the RIPAG Patient Representative violates the non-disclosure agreement. RIPAG reserves the right to take legal action/sanctions (against the individual member and/or the organisation they represent) for breach of the NDA.
- Before any decision to remove someone from being a RIPAG Representative is finalised, the RIPAG Representatives must be informed of the reasons why it is proposed to remove them (this includes an opportunity for open discussion), and at least one month should be allowed for mediation and any concerns raised to be addressed.

**If a Patient Organisation appoints a new individual to represent the organisation in RIPAG, a communication should be sent to the RIPAG Board and to EURORDIS. In this case, the procedure of inclusion of the new candidate will start from the beginning (as defined in the section above: RIPAG representatives).**

**If a RIPAG Representative is no longer representing the patient organisation they joined RIPAG with, they may remain in their current position providing they represent another patient organisation which is already a RIPAG member.**

### **Voting/ eligibility**

In all cases of voting, each Council/Board member may cast one vote. If they are unable to attend, they may vote via proxy. Failure to vote in person or via proxy at the time of the vote, means the member forfeits their right to vote. The outcome of each vote will be based on a simple majority unless otherwise specifically stated. In the event of a tie, the item voted on is not accepted. All voting is confidential and not to be disclosed. Only full members<sup>8</sup> are eligible to vote.

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<sup>8</sup> By default, any member who meets all eligibility criteria is a full member and has full voting rights. Any membership that has been temporarily granted via an exception, is regarded as a partial/temporary membership until the full criteria has been met. Partial membership does not entitle the member to the full rights associated with full membership. In future, there should be NO exceptions to the eligibility criteria. This will remove the need for any partial/temporary memberships.

## **RIPAG Council**

The collection of RIPAG Representatives. For practical reasons the council is limited to twenty-two RIPAG Advocates, two RIPAG Representatives per RITA Working Group. However, to prevent overrepresentation, there should be a maximum of 6 RIPAG patient representatives per disease arm.

To become a Council member, the RIPAG Representative must be voted on by the RIPAG Board.

Only a maximum of three RIPAG representatives can be appointed from the same organisation/federation.

The RIPAG Council appoints two RIPAG Representatives per arm to be included in the RIPAG Board.

## **RIPAG Board**

There are eight board members, two for every arm in the RITA ERN: primary immunodeficiencies, auto inflammatory and autoimmune and paediatric rheumatology.

The RIPAG Board is elected by members of the RIPAG Council. Each RIPAG Board member is identified by the RIPAG Council members of that particular arm. RIPAG Council 'PID-members' will elect the RITA board members for primary immunodeficiencies, autoinflammatory members for autoinflammatory, etc. In the event that there are only two Council members for an arm then by default both are automatically elected to the RIPAG board. However, whenever there are more than two members per arm, then an election must be held.

It was agreed within RITA that one RIPAG Board member per arm will have a seat on the RITA Board. The two RIPAG Board members of each arm will identify one member that that will represent their arm in the RITA Board. In case any RITA Board member is not able to participate in a meeting, he/she can appoint another member of the RIPAG Board to attend the meeting.

## **Working Groups**

RITA has 11 working groups. RIPAG will try to be present in all working groups. If a RIPAG Representative wishes to engage with a specific RITA Working Group, they should send a letter of motivation to the RIPAG Board, who will discuss and agree on the inclusion of the RIPAG Representative in a specific Working Group.

One of the 11 WGs is the patient organisation WG. There is a Chair and a Vice-Chair representing the Patient Organisation working group. If the Vice-Chair is not on the Board, they will be invited to attend the RIPAG Board meetings as a guest, so that they are informed of what is going on.

## **Steering Committee**

EURORDIS has set up an ePAG Steering Committee which is a transversal committee of ePAG Advocates from each of the 24 ePAGs.

The ePAG Steering Committee's role is to:

- Peer-learning from each other by sharing their experience and knowledge from being active in the 24 ERNs;
- Provide strategic advice to inform and prioritise advocacy activities on behalf of all ePAGs and inform on areas of support and training needs to focus EURORDIS support and advocacy activities based on their collective needs.

Each ePAG can delegate 1 representative and 1 alternate to participate in the activities of the ePAG Steering Committee. Both ePAG Representatives are asked to participate in the meetings and the activities of the Steering Committee, providing regular updates to the RIPAG Board. The RIPAG Board appoints the 2 ePAG Representatives that will represent RIPAG in the ePAG Steering Committee.

If either the representative or the alternate resigns or is removed from their position, the RIPAG Board will have to vote on a new representative.

The ePAG Steering Committee will run for five years before the representatives are renewed/replaced.

The RIPAG Board can decide, at any time, to remove and/or replace the ePAG Representative(s) involved in the ePAG Steering Committee for RIPAG:

- if an ePAG Representative is not active in the ePAG Steering Committee;
- if an ePAG Representative is not participating in the ePAG Steering Committee meetings;
- if an ePAG Representative is not reporting the activities of the ePAG Steering Committee to the RIPAG Board.

In this case, the RIPAG Board will inform the ePAG Representative and if the ePAG Representative will not comply with the request of the RIPAG Board, the RIPAG Board will remove them from the role in the ePAG Steering Committee, informing EURORDIS and the RIPAG Council.

## COMMUNICATIONS

### RIPAG Members

The RIPAG council will make sure all members have easy access to the council for questions and input.

### RIPAG Representatives

The RIPAG Representatives are united in the RIPAG Council and therefore communicate according to the Council's schedule.

### RIPAG Council

The RIPAG Council will have a teleconference every two months or more often if needed. On top of that, each individual council member is responsible for keeping his or her peers optimally informed. Quarterly, the Council will report in writing to the RIPAG board about the progress and ongoing activities.

### RIPAG Board

The RIPAG Board will have a teleconference a minimum of every quarter.

The RIPAG Board will manage the communications with the RITA Coordinator(s) and Project Manager and will ensure that the RIPAG is informed on the recent communications received.

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These Terms of Reference can only be modified based upon a two-third majority decision of the RIPAG Board.