**RARE AUTOINFLAMMATORY CONDITIONS COMMUNITY - UK (RACC-UK)** 

**Terms of Reference**

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**Terms of Reference**

**BACKGROUND**

**Rare Autoinflammatory Conditions Community - UK (RACC-UK)** is the UK’s patient-run, patient charity for patients and families suffering from **#Rare** Autoinflammatory conditions. We are led by volunteer patients, parents, and experienced Medical Professionals, in the fields of Rheumatology, Immunology and Nephrology.

We also have several closed private Facebook discussion groups and our website forum with over ***400*** members from the UK suffering from **#Rare** Autoinflammatory conditions.

**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.

**RITA** is the European Reference Network for Rare primary immunodeficiencies, autoinflammatory, autoimmune diseases and paediatric rheumatology

**RIPAG** RIPAG (RITA Patient Advocacy Groups) represents the Patient Community for the European Reference Network (ERN) RITA. RACC - UK, are RIPAG members of the [**European Reference Network, Rare Primary Immunodeficiency, Autoinflammatory and Autoimmune (RITA) diseases.**](http://rita.ern-net.eu/)

**NHS Clinical Reference Groups** are “Each NPoC has several Clinical Reference Groups (CRGs) to provide clinical advice and leadership. These groups of clinicians, commissioners, public health experts, patients and carers use their specific knowledge and expertise to advise NHS England on the best ways that specialised services should be provided.

CRGs lead on the development of clinical commissioning policies, service specifications and quality standards. They also provide advice on innovation, horizon scanning, service reviews and guide work to reduce variation and deliver increased value. CRGs, through their Patient and Public Voice (PPV) members, also help ensure that any changes to the commissioning of specialised services involve patients and the public.” (<https://www.england.nhs.uk/commissioning/spec-services/npc-crg/>). We are registered stakeholders for NHS Clinical Reference Groups relevant to Autoinflammatory conditions.

**Medical Advisory Boards** (MAB’s) are provide insight, scientific direction, and expertise to the organisation. The members of the MAB are recognised experts in Autoinflammatory / Periodic Fever Syndromes from leading academic and medical institutions around the UK. Each of them devotes their time and expertise to improving the lives of people with Autoinflammatory conditions / periodic fever syndromes. (<https://www.pulmonaryfibrosis.org/our-role/leadership/medical-advisory-board>)

**MISSION**

To relieve the needs of patients, families and carers affected by Autoinflammatory conditions in the UK by:

(a) Providing information, support and advice.

(b) Raising awareness of Autoinflammatory conditions.

(c) Providing data when supporting research in relation to Autoinflammatory conditions.

**GOALS**

· Provide a safe space community for patients, parents and carers both diagnosed and undiagnosed with Autoinflammatory Conditions within the UK.

· To signpost and enable discussions amongst patients, parents, carers and the public around finding genetic testing for the conditions and reaching a full diagnosis as early as possible.

· To signpost and enable discussions among patients, parents, carers and the public around accessing treatment through the NHS.

· To raise awareness of Autoinflammatory conditions within the UK by sharing patients’ stories via social media, blogging, websites and potentially leaflets etc. Leaflets will be given to hospitals around the UK to inform patients of our group.

**OBJECTIVES**

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

• 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 and COMMUNICATIONS**

**The organisation is structured as follows:**

1. **Board of Trustees** are members with voting rights, who are Patient Representatives. They volunteer their time to provide insight, direction and expertise to the organisation. There must be no less than three Trustees and no more than five Trustees within the organisation.
2. **Patient Advisory Committee** is a committee made up of members who are either Patients or Carers without voting rights, who have a diagnosed Autoinflammatory Condition who volunteer their time to influence the work of the organisation.
3. **Educational Advisory Committee** is made up of members with no voting rights who volunteer their time to provide insight, direction and educational expertise to the organisation. The must have a professional background in Education from birth to adulthood.
4. **Medical Advisory Board** (MAB) is made up of members with no voting rights to who volunteer their time to provide insight, scientific direction, and expertise to the organisation. The members of the MAB are recognised experts in Autoinflammatory / Periodic Fever Syndromes from leading academic and medical institutions around the UK. Each of them devotes their time and expertise to improving the lives of people with Autoinflammatory.
5. **Patients & Families** are members of the organisation with no voting rights who may receive guidance and support from the organisation. They may or may not have a diagnosis but must be symptomatic of Autoinflammatory conditions.

**EXPECTATIONS**

**Board of Trustees are expected to:**

• collaborate on specific tasks (e.g. respond to surveys),

• disseminate information about the organisation across their wider patient community,

• be consulted occasionally for feedback, and

• be kept informed on the development of the organisation, its beneficiaries and of the advisory committees..

• act in the interests of a relevant specific Autoinflammatory community.

• be eligible by law to be a trustee under the Charity Commission’s criteria.

To become a Trustee of the organisation, applicants should contact the current board by email (info@raccuk.com). The organisation should indicate that it wishes to be engaged

**Patient Advisory Committee members are expected to be:**

* individuals who are patients or caregivers of patients with a diagnosed Autoinflammatory condition. They liaise between the organisation and the committee to ensure true and equitable representation of the patient voice in RACC-UK and to guarantee proper feedback from RACC-UK to the patients.

**Educational Advisory Committee members are expected to be:**

* Individuals who are professionals or former professionals of an educational organisation. They liaise between the organisation and the committee to ensure true and equitable representation of the patient voice in RACC-UK and to guarantee proper feedback from RACC-UK to the patients.
* Individuals are also expected to have knowledge of Safeguarding Children and some experience of working with Children with Special Educational Needs and Disabilities.

**Medical Advisory Board members are expected to be:**

* Individuals who are professionals or former professionals of a health organisation (NHS) connected to the specialist area of Autoinflammatory conditions. They liaise between the organisation and the committee to ensure true and equitable representation of the patient voice in RACC-UK and to guarantee proper feedback from RACC-UK to the patients.

RACC-UK collaborate with 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.

Collectively, committee members and board members are committed to being involved in the network activities and they are active in the RACC-UK governance structure including its work streams and working groups.

Representatives also commit to adhere to the following core values:

• respecting the mission of the organisation 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,

• having the capacity to be active in RACC-UK and report regularly on their activities.

Those who are interested in becoming involved in one of the committees should:

• provide a short biography,

• complete the google form,

• provide evidence of their professional status, or where a patient, provide information about their diagnosis,

• where a conflict of interest may occur, applications should provide a conflict-of-interest statement.

Failure to meet ALL of the requirements is an automatic decline.

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

*A committee representative appointment in RACC-UK comes to an end if:*

• the Patient Representative sends a notice of resignation to the RIPAG Board,

• the Board of Trustees appoints a new individual to represent the organisation in RACC-UK;

• the Board of Trustees decides that it is in the best interests of RACC-UK that the representative in question should be removed.

• Before any decision to remove someone from being a RACC-UK Representative is finalised, the Board of Trustees 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 the Board of Trustees appoints a new individual to represent the organisation in RACC-UK, a communication should be sent to all patients, families and the committee members. In this case, the procedure of inclusion of the new candidate will start from the beginning.**