

REPORT OF THE TRUSTEES AND UNAUDITED FINANCIAL STATEMENTS FOR
THE YEAR ENDED 22nd FEBRUARY 2025 FOR

RARE AUTOINFLAMMATORY CONDITIONS COMMUNITY – UK (RACC-UK)

(Charitable Incorporated Organisation (CIO): Foundation Model)



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REGISTERED CHARITY NUMBER IN ENGLAND AND WALES: 1184846

REGISTERED COMPANY NUMBER IN ENGLAND AND WALES: **CE018491**

REPORT OF THE TRUSTEES FOR THE YEAR ENDED 22ND FEBRUARY 2025

As a Foundation Model of a Charitable Incorporated Organisation, Trustees are the people responsible for controlling the work, management, and administration of the charity on behalf of its beneficiaries. Generally, trustees are treasurer, chair, board member etc. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)

OBJECTIVES AND ACTIVITIES

Objectives and aims: 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.

Charity Constitution

Recruitment and appointment of new trustees:

There should be not less than 3 nor more than 5 appointed trustees.

Apart from the first charity trustees, every trustee must be appointed two years by a resolution passed at a properly convened meeting of the charity trustees.

In selecting individuals for appointment as charity trustees, the charity trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO.

Trustees cease to hold office if he or she:

- a) retires by notifying the CIO in writing (but only if enough charity trustees will remain in office when the notice of resignation takes effect to form a quorum for meetings).
- b) is absent without the permission of the charity trustees from all their meetings held within a period of six months and the trustees resolve that his or her office be vacated.
- c) dies.
- d) in the written opinion, given to the company, of a registered medical practitioner treating that person, has become physically or mentally incapable of acting as a director and may remain so for more than three months.

- e) is disqualified from acting as a charity trustee by virtue of sections 178-180 of the Charities Act 2011 (or any statutory re-enactment or modification of that provision)

Organisational Structure

The organisation has three charity trustees as its first trustees who meet regularly to discuss the charity's activities and impact.

(1) The members of the CIO shall be its charity trustees for the time being. The only persons eligible to be members of the CIO are its charity trustees. Membership of the CIO cannot be transferred to anyone else.

(2) Any member and charity trustee who ceases to be a charity trustee automatically ceases to be a member of the CIO.

Decision Making

Taking of decisions by charity trustees

Any decision may be taken either: at a meeting of the charity trustees; or

- by resolution in writing [or electronic form] agreed by a majority of all the charity trustees, which may comprise either a single document or several documents containing the text of the resolution in like form to which the majority of all the charity trustees has signified their agreement. Such a resolution shall be effective provided that.
- a copy of the proposed resolution has been sent, at or as near as reasonably practicable to the same time, to all the charity trustees; and
- the majority of all of the charity trustees has signified agreement to the resolution in a document or documents which has or have been authenticated by their signature, by a statement of their identity accompanying the document or documents, or in such other manner as the charity trustees have previously resolved, and delivered to the CIO at its principal office or such other place as the trustees may resolve [within 28 days of the circulation date]

Decisions which must be made by the members of the CIO.

(1) Any decision to:

(a) amend the constitution of the CIO.

(b) amalgamate the CIO with, or transfer its undertaking to, one or more other CIOs, in accordance with the Charities Act 2011; or wind up or dissolve the CIO (including transferring its business to any other charity) must be made by a resolution of the members of the CIO (rather than a resolution of the charity trustees).

(2) Decisions of the members may be made either: (a) by resolution at a general meeting; or (b) by resolution in writing, in accordance with sub-clause (4) of this clause.

(3) Any decision specified in sub-clause (1) of this clause must be made in accordance with the provisions of clause [28] (amendment of constitution), clause [29] (Voluntary winding up or dissolution), or the provisions of the Charities Act 2011, the General Regulations, or the Dissolution Regulations as applicable. Those provisions require the resolution to be agreed by a 75% majority of those members voting at a general meeting or agreed by all members in writing.

(4) Except where a resolution in writing must be agreed by all the members, such a resolution may be agreed by a simple majority of all the members who are entitled to vote on it. Such a resolution shall be effective provided that:

(a) a copy of the proposed resolution has been sent to all the members eligible to vote; and

(b) most members have signified its agreement to the resolution in a document or documents which are received at the principal office within the period of 28 days beginning with the circulation date. The document signifying a member's agreement must be authenticated by their signature, by a statement of their identity accompanying the document, or in such other manner as the CIO has specified. The resolution in writing may comprise several copies to which one or more members has signified their agreement. Eligibility to vote on the resolution is limited to members who are members of the CIO on the date when the proposal is first circulated.

Induction and training of new trustees

The charity trustees will make available to each new charity trustee, on or before his or her first appointment:

(a) a copy of the current version of this constitution; and

(b) a copy of the CIO's latest Trustees' Annual Report and statement of accounts

New trustees will also be expected to carry out basic Safeguarding Children and Safeguarding Adults in line with the organisation's safeguarding policy.

Key management remuneration

- There are no salaried staff members.
- Only core running costs are budgeted predicted on the last financial year of the organisation.

Risk Management

As governed by Charity Commission in England and Wales, it is the duty of trustees to identify risks and ensure that appropriate and reasonable measures are taken to prevent fraud and mistakes. Trustees compile a register of risks and monitor as such in line with the 'COMPLIANCE TOOLKIT: PROTECTING CHARITIES FROM HARM Chapter 3: Fraud and financial crime – summary' (2016)¹

¹ [Compliance Toolkit: Protecting Charities from Harm - Chapter 3: Fraud and financial crime summary](#)

There is also a minimum of two signatories on the Charity Bank account to mitigate fraud and crime.

Introduction

Launched in 2019, RACC-UK is a registered charity with a mission to improve the lives of those living with a Rare Autoinflammatory Condition.

We are based out of Oxford but offer support to patients from across the UK. Since our registration we have been able to help over 100 individuals and are looking to expand our activities to provide support to an even greater number of individuals.

RACC-UK was launched by Rachel Rimmer following her experience living with a rare autoinflammatory condition with the ambition to be a Platform for assisting other individuals suffering from a rare autoinflammatory condition.

The Rare Autoinflammatory Disease Landscape

Rare Autoinflammatory Conditions make up a sub-section of rare diseases and affect around 5 out of every 10,000 people. They can be defined as clinical disorders marked by abnormally increased inflammation caused by dysfunction in the innate immune system. Autoinflammatory conditions are often caused by genetic faults that cause our innate immune system to produce cells which secrete types of cytokines called Interleukins. Cytokines play an important part in inflammation and immunity. However, in Autoinflammatory conditions, there is an over production of cytokines causing a hyper inflammatory response which can damage organs and joints. The most common type of interleukin cytokines involved in Autoinflammatory conditions are Interleukin – 1 alpha and Interleukin – 1 beta. The biological therapies (injections) used to treat Autoinflammatory conditions suppress the over production of cytokines (Interleukin 1), minimising inflammation and prevents damage to organs and joints. These are also known as Interleukin 1 blockers.

A disease is defined as rare if it affects fewer than 1 in every 2,000 of the general population; however, whilst rare diseases may be individually rare, they are collectively common, with 1 in 17 people being affected by a rare disease at some point in their lives (this amounts to over 3.5 million people in the UK).

With advances in research, we are increasingly recognising more conditions and to-date have identified over 7,000 rare diseases; however, with this many conditions it can be hard to get a diagnosis and to receive appropriate treatment.

Recent advances in technology alongside changes to government policy have looked to improve the care for patients with rare diseases. This includes projects focused on improved diagnosis such as the 100,000 genomes project and UK government initiatives such as the UK Rare Disease Framework, the 2024 England rare diseases action plan, and the All-Party Parliamentary Group on Rare, Genetic and Undiagnosed conditions.

There are also international projects focused on developing the education around rare diseases and establishing international research collaborations. The European Reference Networks (ERNs) have been established to allow knowledge sharing in relation to specific cases and include participating centres across 28 countries including the UK.

Whilst these projects have made strides in improving the treatment of individuals with rare diseases, there is still some progress to be made. RACC is on a mission to support patients, parents, and careers living with a rare autoinflammatory disease to ensure a better future for all.

Public benefit: Nothing in this constitution shall authorise an application of the property of the CIO for the purposes which are not charitable in accordance with [section 7 of the Charities and Trustee Investment (Scotland) Act 2005] and [section 2 of the Charities Act (Northern Ireland) 2008]

The trustees have complied with Section 17(5) of the Charities Act 2011 and have had due regard to the guidance on the Public Benefit by the Charity Commission when exercising relevant powers and duties.

Our Strategic Objectives

1. To be a source of support for patients, parents and carers living with an autoinflammatory condition

Whilst globally there have been strides in advancing the diagnosis, treatment and management of Rare Autoinflammatory Conditions, it can be difficult for all patients, parents, and carers to know where to go to access the necessary physical, emotional and financial support. No one condition is the same and often the process of getting to a diagnosis can be long and daunting. Furthermore, once a diagnosis has been received patients will generally have to take on the huge responsibility of managing the coordination of care across different consultants and different centres (Patients may have around 10 different consultants involved in their care, many working in different health care trusts). This burden can really take its toll and can often lead to feeling isolated and overwhelmed. It's vital that patients feel like they have somewhere to go for support and we want to be able to provide a platform that patients can turn to.

Our Objectives:

- To provide advice on how to access relevant Disability/ Sickness benefits for financial support (e.g. Disability Living Allowance/ Personal Independence Payment, Employment and Support Allowance and Carers Allowance).
- To provide sessions on how to complete forms for seeking financial assistance to signpost patients to support in completing forms and appeals (e.g. Fightback 4 Justice).
- To encourage and provide resources for Patients / Carers / Family members to keep their own home file including all appointments, test results, appointment reports and symptoms diary.
- To organise and facilitate virtual meetups for the community.
- To provide first hand experiences and patient resources that provide some clarity on what to expect.
- To provide a coordinate discussion among patients, parents, carers, and the public around accessing treatment through the NHS.
- To offer 1:1 support session to patients suffering from a rare autoinflammatory disease.

2. To campaign for policies that allow patients to access the necessary treatments.

The UK Rare disease framework looks to outline the government approach to policy around rare diseases including improved coordination of care, access to treatment, and education of healthcare workers; however, with over 7,000 this is not an easy task. With this number of diseases, it is difficult for specialists to be trained in all diseases, and often this expertise is limited to larger cities, creating inequities in patient care and making coordination of care more difficult. RACC will continue to advocate for patients by campaigning for policies that improve patient support (financial, physical and emotional) and advance treatment options.

Our Objectives:

- To advocate for all UK patients, directly or via parents and carers, to have genetic testing and reach a diagnosis for Autoinflammatory Conditions.
- To fight for practices/policies that will allow patients to better access financial support for their condition.
- e.g. encourage Health Care Professionals (HCP's) to provide supporting evidence of patients' medical history
- To advocate for the sharing of Appointment letters and reports among the patient and all HCP's so that all HCP's have the same information and aware of the complex challenges the patient experiences.
- To register as stakeholders in the Clinical Reference Groups with NHS England and NICE to enable us to influence Drug Policy and Guidance in line with recent research.
- To increase our involvement in BANNAR network, allowing RACC to input on behalf of patients and shape Adolescent Rheumatology services.
- To Implement an outcome measurement framework within our network that can serve as a source of information for policy makers

3. To be a source of education on Autoinflammatory conditions including the emotional and physical effects of living with a Rare Autoinflammatory condition.

Although we have started to see increased research into rare diseases over recent years, knowledge of these conditions remains low and often Primary and Emergency care professions will not have a good understanding of these conditions. This can be detrimental to patients suffering from a rare autoinflammatory disease through delayed diagnosis and incorrect treatment. It is thought that around 50% of the 30 million people living with a rare disease in Europe are yet to receive a diagnosis, and delayed treatment can cause long-term damage to organs and joints as well as the onset of Amyloidosis. Beyond the physical impact, lack of a diagnosis and misunderstanding of rare autoinflammatory conditions can be extremely scary and isolating. Through personal experience, working with individuals suffering from an Autoinflammatory disease, and partnerships with researcher in the field, RACC have begun to develop a deep understanding of the emotional and physical effects of autoinflammatory conditions. Over the next few years, we hope to use this knowledge to provide resources and educate practitioners, policy makers, patients and the public on autoinflammatory conditions including the emotional and physical effects of these diseases on a patient.

Our Objectives:

- To Produce Awareness campaigns through social media that act as a source of information for the public. This will include Patient stories (blogs, anonymous quotes, testimonials), new discoveries, and general educational resources.
- To Provide a space on our website that will contain information about rare autoimmune conditions including current research, and Patient stories (blogs, anonymous quotes, testimonials).

- To produce conferences and workshops for HCP's and AHP's to share what we have learnt about the patient experiences and the realities of living with an Autoinflammatory condition.
- To provide a safe space for patients, parents, and carers both diagnosed and undiagnosed with Autoinflammatory Conditions within the UK to ask questions.
- Provide a platform complete with resources to educate patients, parents, carers, and healthcare professionals on rare autoinflammatory conditions
- To work with Academics in the field to produce a overview (review) of research on rare autoinflammatory conditions that can be accessed by the general public

4. **To support research that advances the knowledge of rare autoinflammatory conditions**

While there is research within Autoinflammatory conditions, including the 100,000 genomes project and numerous other small studies funding is somewhat limited to research grants carried out by current specialists or PhD Students. To our knowledge, there is no statutory funding for research in Autoinflammatory conditions, and it is predominantly supported by pharmaceutical grants or philanthropic pursuits. To make a real difference to the lives of patients we need further research into the treatment and diagnosis of autoinflammatory conditions.

Our Objectives:

- To establish a Patient Database, referencing information from the Patient Registry as well as recording updates at the point of contact.
- To develop clear and concise care plan pathways for monitoring treatment success using data collection and capturing the Patients Quality of Life (QoL)
- To undertake qualitative research, developing surveys that can be used to provide insight into the impact of rare autoinflammatory conditions
- To complete a needs assessment within our community to obtain data that can inform future policy and investment
- RACC-UK's long-term objective is to be able to fund research studies within the UK focused on Rare autoinflammatory conditions. This objective is heavily reliant on grants, donations, and sponsorships but RACC – UK remains determined to support patients to receive an early diagnosis and access to treatment that will prevent multiple hospital admissions. It is our belief that one keyway to do this is to increase the current understanding of these conditions through increased research.

The **UK Rare Disease Framework** was set out in 2021; this is built on the framework from 2013 and aims to target 4 key areas:

- Improve diagnosis of rare diseases - building on advances in diagnostic technologies, particularly through genomics and data analysis

- Increase awareness of rare diseases among health-care professionals - to build on the UK's world-leading research and life sciences to improve access to innovative treatments and specialist care
- Better coordination of care - management of rare diseases may require the expertise of multiple different specialists spread across the globe. They aim to work on coordinating care across different teams
- Improving access to specialist care, treatments and drugs- work collaboratively to ensure that the needs of rare disease patients are appropriately reflected across wider government policy, including therapeutics, mental health and social care.

References:

100,000 Genomes: <https://www.genomicsengland.co.uk/initiatives/100000-genomes-project>

<https://www.genomicseducation.hee.nhs.uk/rare-disease-education-hub/#toggle-id-1>

The Westminster All Party Parliamentary Group on Rare, Genetic and Undiagnosed conditions: <https://geneticalliance.org.uk/westminster-appg/#:~:text=The%20APPG%20helps%20to%20give,in%20just%20a%20few%20clicks>

England Rare Disease Action Plan: <https://hansard.parliament.uk/commons/2024-02-29/debates/24022932000010/EnglandRareDiseasesActionPlan2024#:~:text=The%20National%20Conversation%20on%20Rare,improved%20access%20to%20specialist%20care%2C>

The long journey to a rare disease diagnosis: <https://projects.research-and-innovation.ec.europa.eu/en/horizon-magazine/long-journey-rare-disease-diagnosis>

Hausmann, J.S., Lomax, K.G., Shapiro, A. *et al.* The patient journey to diagnosis and treatment of autoinflammatory diseases. *Orphanet J Rare Dis* **13**, 156 (2018). <https://doi.org/10.1186/s13023-018-0902-7>

Ciccarelli F, De Martinis M, Ginaldi L. An update on autoinflammatory diseases. *Curr Med Chem*. 2014;21(3):261-9. doi: [10.2174/09298673113206660303](https://doi.org/10.2174/09298673113206660303). PMID: 24164192; PMCID: PMC3905709.

Rech J, Schett G, Tufan A, Kuemmerle-Deschner JB, Özen S, Tascilar K, Geck L, Krickau T, Cohen E, Welzel T, Kuehn M, Vetterli M. Patient Experiences and Challenges in the Management of Autoinflammatory Diseases-Data from the International FMF & AID Global Association Survey. *J Clin Med*. 2024 Feb 20;13(5):1199. doi: [10.3390/jcm13051199](https://doi.org/10.3390/jcm13051199). PMID: 38592017; PMCID: PMC10931825.

ACHIEVEMENT AND PERFORMANCE

Internal

RACC – UK board of trustees remained stable at three individuals with direct patient knowledge and experience, educational knowledge and experience. We saw the organisational strategy develop to strengthen our objectives and deliver our charitable purpose. Trustees are mindful of the growth and transition of the organisation in 2027 as the current chair will step down. Actions are being taken to ensure that this transition shall be smooth.

Trustees have acknowledged the current website is basic and needs some significant development for usability and accessibility. This reflects the overall growth of the organisation in its entirety. Look forward to 2025 – 2026, Trustees shall focus their efforts on securing funding for this project.

The organisation has continued to develop stronger relationships with Medical Professionals across the UK, collaborating in research² and improving the patient experience³ for the organisation's beneficiaries.

The financial business has been strong this year with three key fundraising events by supporters. Trustees recognise that funding has been a significant concern in previous years and would like to thank the individuals for their generous support.

In terms of communication and transparency, there is much work still to do to better inform beneficiaries of the work the charity does. Much of this will be embedded into the website which is one of the key assets for information, support and resources available to individuals and families. Other methods of communication include a quarterly newsletter, a social media planner, increasing the number of volunteers to support the work of the organisation. Trustees will seek to find solutions utilising technology to meet these goals.

Support Services provided by the organisation:

- Social media forums currently provide signposting information, a space for individuals to connect with others, reach out for additional support from the organisation which is better tailored to the individual needs.

² [Pregnancy-related issues in rare and low-prevalence diseases: results of ERN transversal working group on pregnancy and family planning survey | Orphanet Journal of Rare Diseases | Full Text](#)

³ [Recommendations for Transitioning Young People with Primary Immunodeficiency Disorders and Autoinflammatory Diseases to Adult Care - PubMed](#)

- We provide free 1:1 consultation for individuals and their families regardless of which stage of the diagnosis pathway they are at.
- Supporting letters are available to individuals after a 1:1 consultation and consent forms are completed. To date we have written supporting letters to a range of professionals for accessing genetic testing, advocating for specialised medication review based on the activity of their condition not being well controlled, supporting letters to address concerns of poor attendance being questioned in school and in employment.

External

Whilst significant efforts have been made to improve the overall patient experience, there are many concerns that continue to be raised across various cohorts of Autoinflammatory conditions.

Going concerns:

- Accessing genetic testing - different approaches in care and theories affects individual access to genetic testing.
- Diagnosis is heavily reliant on pathogenic variants from genetic testing
- Treatment efficacy is heavily reliant on biomarkers (CRP / SAA)
- Lack of continuity of care services. Patients see different HCPs at each appointment. Is this due to high staff turnover?
- Accessing social security benefits due to the rarity of the conditions
- Maintaining employment due to absences
- Attendance issues in school
- Identifying individuals and collecting quantifying evidence remains a significant challenge for the organisation due to not have direct NHS access, no national registry available to ascertain numbers of cohorts across the UK. As the organisation grows, we would like to see a role out of a National Registry Database for all Autoinflammatory conditions.

Patients across the UK continue to receive disjointed care across the NHS. There are some hospitals that hold Fever Clinics such as Manchester, Leeds, Cambridge, Birmingham and Sheffield. These centres have access to genetic testing for Autoinflammatory conditions. These samples are sent to various laboratories across England such as Manchester, Sheffield and London. It is unclear if all laboratories use the same technology. This is something for RACC – UK to ascertain moving forward. To access specialist treatments, patients are required to attend specialist clinics at Great Ormond Street Hospital and the National Amyloidosis Centre, both in London, for Anakinra and Canakinumab. Anakinra and Canakinumab are known as biological therapies, blocking the over production of the Interleukin -1b pathway. Those treatments remain a second line treatment when NSAIDS or DMARDS have failed. Some patients may receive Colchicine before or alongside

As stated on their website, the National Amyloidosis Centre⁴: “Our service is funded by NHS England. Charges apply only to private patients and genetic requests from

⁴ [Fever syndromes | Royal Free London](#)

Ireland, Wales and Scotland. Charges are: £150 for carrier and predictive testing of known mutations, and £400 for screening of a single gene using Sanger sequencing method. NGS gene panels for hereditary amyloidosis or systemic autoinflammatory diseases (SAIDs) are £700.” Molecular Genetic Testing | Centre for Amyloidosis and Acute Phase Proteins - UCL – University College London

As of this business year, many monogenic Autoinflammatory genes have been added to the list of the Generation Study Newborn Genomes Programme | Genomics England. The study is following on from the 100,000 Genome Project delivered by NHS England

Financial Business 23rd February 2024 – 22nd February 2025

Balance Brought Forward	£ 1,326.89
Income	£ 6,497.97
Outcome	£ 2,685.70
Balance at end of year	£ 5,139.16

Registered Office

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Bank Address

Santander, Bridle Road, Liverpool, Merseyside, L30 4GB

Insurance

Zurich Insurance for Charities – Public Liability Insurance and Trustee Indemnity Insurance

Independent Examiner

Not Applicable

Solicitors

Not Applicable

Approved and signed by

Rachel Rimmer

Rachel Rimmer (Chair Trustee)

M. Telman

Mark Telkman (Oct 13, 2025 17:09:47 GMT+1)

Mark Telkman (Patient Engagement Trustee)

Date 10/10/2025