

**REPORT OF THE TRUSTEES AND**  
**UNAUDITED FINANCIAL STATEMENTS FOR THE**  
**YEAR ENDED 22<sup>ND</sup> FEBRUARY 2023**  
**FOR**  
**RARE AUTOINFLAMMATORY CONDITIONS COMMUNITY – UK (RACC-UK)**



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**FOR THE YEAR ENDED 22<sup>ND</sup> FEBRUARY 2023**

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## **REPORT OF THE TRUSTEES FOR THE YEAR ENDED 22<sup>ND</sup> FEBRUARY 2022**

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.

Significant activities: There are approximately 26 Autoinflammatory conditions that are rare and genetic identified as errors of the innate immune system. Due to the rarity and complexity of the conditions, they are often overlooked by doctors, researchers, and the public. Symptoms are like those of Autoimmune conditions involving the adaptive immune system and the only way to diagnose Autoinflammatory conditions is through Genetic testing.

*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.

## **ACHIEVEMENT AND PERFORMANCE**

### *Charitable activities*

RACC – UK is led by a Board of Trustees. The work is driven by patients, families, carers, and experienced medical professionals, in the fields of rheumatology, immunology and nephrology. RACC – UK is also represented by Rachel Rimmer as a RIPAG member of the European Reference Network, Rare Primary Immunodeficiency, Autoinflammatory and Autoimmune (RITA) diseases. In addition to this, RACC – UK are registered stakeholders for NHS Clinical Reference Groups relevant to Autoinflammatory conditions.

Patients in the UK with Autoinflammatory conditions have often endured a long delay to diagnosis which impacts on long-term health and quality of life. Autoinflammatory conditions are Rare genetic conditions which often leave patients feeling vulnerable and isolated with little support. RACC – UK believes that no patient should have to suffer on their own.

Today, we care for around 400 patients affected by a range of Autoinflammatory conditions living in the UK, as well as their families and carers. Our services include peer support (group support), 1:1 support, educational support not only of understanding Autoinflammatory conditions but also liaising with schools for school support, liaising with medical professionals, supporting patients on how to navigate the referral processes in the NHS and ensuring they have relevant professionals involved to diagnose and treat their conditions.

Our current services are intermittent, and we realise that having more human resources would be beneficial in helping us to deliver our services to patients, families, and carers. Over the past year, there has been increase of families requiring 1:1 support session. These sessions have ranged from supporting letters for accessing genetic testing and referrals to specialists via their GP's; supporting letters to support benefit claims; supporting letters for Educational Health and Care Plans in schools. We have also seen a small increase in professionals in schools, social care and primary care requesting further information about the conditions to better support families. The [Organisation Strategy](#) needs to be updated for the next 3 financial years.

Due to the Cost-of-Living Crisis, two £25 food vouchers were given out to two families during a half term holiday. This was due to the rise of inflation and the increased cost of energy prices. As a small Charity, we cannot commit to this moving forward due to lack of funds. However, we will ensure that families receive support from other networks where possible. The Cost-of-Living Crisis remains an uphill battle and the Charity remains committed to family support despite the lack of financial stability.

### *Internal and external factors:*

Rare Autoinflammatory Conditions Community – UK's board of trustees consisted of direct patient knowledge and experience, educational knowledge and experience, carers knowledge and experience. The skills and knowledge among the board was the main strength in delivering the Charity objectives.

The three-year strategy has been useful for the Board of Trustees to prioritise the organisations work; however, this must be revised for the next three years, ensuring the organisation remains compliant with Charity Law throughout.

Relationships with Medical Professionals has significantly improved. We are delighted with the response from Medical Professionals willing to work with us to support our work, supporting patients and families. As we look to 2023 – 2024, we will be aiming to develop a new Autoinflammatory Professional Network for Medical Professionals.

#### Risks:

- I. *Financial aspects* of the organisation are critical and recruitment to cover these areas remains problematic due to the current climate, Cost-of-Living Crisis in the UK. Funds remain low and we did not any grants. The Board of Trustees is remains committed to strengthen the finances of the organisation. There is an opportunity for the Charity to connect with a Pharmaceutical company and may financially benefit from doing so, however this is still in it's early planning stages.
- II. *Trustee retention* has once again been problematic. There were contributing factors ongoing from the last two financial years of the organisation being targeted in a hate campaign on social media. This appears to have disappeared now. Trustees who held their positions also had their own career changes due to lost across the UK. In turn, trustees' commitments changed, and they could no longer support the charity as a Trustee.
- III. *Main areas for recruitment* of Trustees are 'Treasurer' for the financial business development. Unfortunately, we have had poor engagement with this opportunity, so the Board need to develop a new strategy for recruitment and retention.
- IV. *Health status of Trustee's: Some trustees are patients of rare diseases themselves, their commitment to the Charity can be somewhat restricted at times.* This adds pressure to delivering charitable aims and at times, projects are having to be scaled back.

#### Risk Mitigation

- I. *Finances: funds* remain low but sufficient for core costs. Additional projects will require grants and donations. The Board of Trustees shall develop a financial business strategy in November 2023.
- II. *Trustee retention:* The current trustees are working hard to recruit and fulfil positions with specific skill sets. The chair has connected with local voluntary organisations to advertise; as well as asking the Patient Engagement Officer to publish across social media. Unfortunately, we have received a lot of interest in the positions advertised, positions offered and a lack of engagement through the recruitment criteria. This

means that time has been spent having to re advertise for positions which were previously taken, delaying our commitment to other projects. It is vital that the team develops a new strategy for recruitment and can overcome the previous challenges.

III. The Charity seeks to recruit a Treasurer for a minimum of three years.

### Partnerships

External partnerships continue to be essential in helping us to deliver our objectives. Working in collaboration with other organisations not only helps us to raise awareness but strengthens our work and achieve our objectives.

Rare Autoinflammatory Conditions Community – UK became members of the [European Reference Network for Rare Immunodeficiency Autoinflammatory, Autoimmune Diseases](#) in 2018, with direct patient representation by one of its trustee's involvements. Between 2018 and 2021 the projects were slow at getting going. Since 2021, we have been heavily involved in the RITA Transition of Care working group, developing EU guidelines for Transition of Care in Adolescents for Primary Immunodeficiency and Autoinflammatory conditions.

[FMF and AID Global Association](#) To better support our members, RACC - UK we remain affiliated to the FMF & AID Global Association. Through our partnership, we can raise awareness better. It also enables us to pool resources and benefit from various support programs developed by FMF & AID and their affiliates. September saw a strong awareness month delivered by FMF & AID Global Association, their affiliates across the world.

[Genetic Alliance UK](#), our membership is annually approved since November 2019. This enables us to reach out further to families who may be undiagnosed, as well as being involved in the All-Party Parliamentary Group for Rare, Undiagnosed and Genetic Conditions.

[Beacon](#), deliver training sessions for patient organisations within the Rare Disease community. The training sessions are not only delivered in house but involve many third parties with a wide range of knowledge and expertise. Due to other commitments with the increasing demand of patient and family support, we have not been able to attend many virtual workshops as we have in the past. Attending these events builds confidence in our work, helps to direct our strategies, and strengthen our skill set.

[Council for Disabled Children](#) are a well-known organisation within England and Wales, providing support to disabled children and their families. In an addition this, CDC influence policy and guidance on a national level, working alongside other charities and government officials. In June 2022 we were approved to join the [Children and Young People's Health Policy Influencing Group \(HPiG\)](#) along with 60 – 70 other Charities. Since 2021, the group has been working on the new [Health and Care Bill](#) which recently received Royal Assent. Following this work, the group is now working on the Major Conditions Strategy.

[NCVO](#) we continue to be members of The National Council for Voluntary Organisations (NCVO). NCVO provides resources to Non – Profit Organisations like RACC – UK, for a range of business areas including recruitment, policy, and training opportunities.

[BANNAR Network](#) BANNAR started in 2013. Since 2020 the network has been ‘nested’ within Versus Arthritis. BANNAR are a group of professionals from medical, nursing, allied health professional and third sector backgrounds working in adolescent and young adult (aged 10-24) rheumatology. BANNAR are now looking to create a sub – working group with a focus on Mental Health among Adolescents in Rheumatology. This is still in the development stage but there are some great opportunities for Patient Organisations to collaborate on a joint Mental Health campaign.

The network aims to:

1. Act as a UK-wide professional network in adolescent and young adult rheumatology research.
2. Empower young people with rheumatic disease (and their families/social networks) to contribute to relevant research and help develop future research priorities.
3. Develop adolescent and young adult rheumatology as an area of research.
4. By working collaboratively, we can do more together to promote best practice, share advice, and feed into research and help to improve paediatric, adolescent, and young adult rheumatology services in the UK.

## **FINANCIAL REVIEW**

### *Financial position*

This third financial year has been challenging, with COVID 19 continuing to restrict our ability to physically take part in fundraising events due to the health of the Chair. Income was generated mainly by some donations. The remaining income was received from donations. Although the income remains significantly low and does pose a financial challenge for the next few years, we are confident that our third year shall allow us to increase our income with access to grants and further donations. The balance carried forward shall go towards the core running costs of the organisation.

### *Principal funding resources*

The principal funding source in this financial year was from funds left over from the remaining financial year with a few donations trickling in throughout the financial year.

### *Reserves*

The organisation holds sufficient reserves to cover the core running costs for the next financial year to the sum of. Due to the organisation's size and current financial climate due to the pandemic, there is no reserves policy to date. This has not yet been possible to develop however, once funds begin to significantly increase, a reserves' policy shall be created and implemented.

### *Going concern*

There are sufficient funds to cover the core costs for the next financial year and the trustees remain confident that the organisation's income shall increase to support its future projects. However, the trustees remain dedicated to generating income from grants and fundraising, despite the current climate.

## **FUTURE PLANS**

The organisation's main aim for 2023 - 2024 is to generate income to support the physical development of educational materials for patients and families. This will be delivered through the care plan pathway, alongside patient experts influencing the work, and the direct involvement of the Medical and Scientific Advisory Board. The organisation will also seek to participate in research opportunities, collaborating with Medical Professionals.

The organisation will aim to expand its own board of trustees, bringing in further skills and knowledge to better support the delivery of its objectives. 2023 will see us continuing to respond to the Cost-of-Living Crisis following the pandemic and prioritising the direct patient support among the patient community both nationally and internationally in collaboration with other Patient Organisations.

## **STRUCTURE, GOVERNANCE AND MANAGEMENT**



### Governing Document

The Charity is controlled by its governing document, a constitution for Foundation Charitable Incorporated Organisations (CIO) as defined by the Charity Commission in England and Wales.

The Charity's objects set out in its constitution are:

- (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:*

- (a) There should be not less than 3 nor more than 5 appointed trustees.
- (b) 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.
- (c) 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) (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) (c) dies.
- (d) (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) (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 first 6 months of the organisation's existence.

#### Related Parties

NHS England paid the organisation for its involvement of its project. This was based on how many days / hours it took to complete the project under NHS England's own reimbursement policy.

#### 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)<sup>1</sup>

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

Furthermore, the organisation remains transparent to its patient community, providing weekly updates of its work and achievements. Moving forward we hope to ensure that set budgets are allocated for specific patient engagement activities, overseen by the organisation's trustees, in the form of a Patient and Carers Advisory Board.

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<sup>1</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/571158/Chapter3\\_Summary.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/571158/Chapter3_Summary.pdf)

## **REFERENCE AND ADMINISTRATIVE DETAILS**

Registered Charity in England and Wales: 1184846

Registered Company Number: CE018491

### **Registered Office**

Flat 1,  
24 Swan Street  
Eynsham,  
Oxfordshire,  
OX29 4HU

### **Trustees**

|                  |  |
|------------------|--|
| Rachel Rimmer    | Chair Trustee [2019 – 5 Year term]               |
| Rishi Nursimloo  | Trustee [2021 – Resigned December 2022]          |
| Laurie Abraham   | Trustee [December 2021 – Resigned February 2023] |
| Liza Wrigley     | Trustee [December 2022 – 2 Year Term]            |
| Michelle Erskine | Trustee [February 2023 – 2 Year Term]            |

### **Independent Examiner**

Not Applicable

### **Solicitors**

Not Applicable

**Bank Address:**

Santander  
Bridle Road  
Liverpool  
Merseyside  
L30 4GB

**Insurance**

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

**STATEMENT OF FINANCIAL ACTIVITIES**  
**(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)**  
**FOR THE YEAR ENDED 22<sup>ND</sup> FEBRUARY 2023**

|         |          |
|---------|----------|
| Income  | £1157.81 |
| Outcome | £2359.59 |
| Balance | £508.28  |

**4.1 Which reporting requirements apply to all charities which must register with the commission except charitable companies and CIOs?**

**4.1.1 Charities where the gross income does not exceed £25,000 in the relevant financial year (legal requirement)**

Basis of preparation: accounts must be prepared either on the receipts and payments or the accruals basis. If on an accrual's basis, they must be prepared in accordance with the 2008 Regulations and the SORP. The commission provides packs for non-company charities preparing their accounts on a receipts and payments or accrual accounting basis which are available on GOV.UK. These provide a template to produce accounts in the required form.

External scrutiny: there is no requirement to have the accounts independently examined or audited, unless the charity's governing document stipulates it, but the commission does have the power to require an audit in exceptional circumstances.

Type of trustees' annual report: a trustees' annual report must be prepared (unless excepted from registration) but it may be simplified (see [section 7](#)).

Information to be sent to the commission: these charities should not send the commission a copy of their trustees' annual report and accounts unless it asks for them.

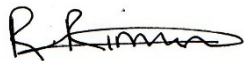
They must, however, file an annual return with the commission online within ten months of the end of their financial year if their yearly income is over £10,000.

If the income is less than £10,000, they can use the annual return form to update their register details, which includes trustee details. The commission sends an annual return

notification to the named contact on its records shortly after the end of the charity's financial year.<sup>2</sup>

This report has been prepared in accordance with The Charities (Accounts and Reports) Regulations 2008

Signed on its behalf by:



Rachel Rimmer [Chair Trustee]

29/11/2023

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<sup>2</sup> <https://www.gov.uk/government/publications/charity-reporting-and-accounting-the-essentials-cc15b/charity-reporting-and-accounting-the-essentials#specific-reporting-requirements-for-different-types-of-charity>