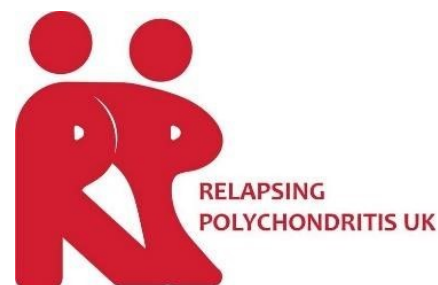




Fifth Annual Report and Accounts

Reporting Period

1/04/2022 to 31/03/2023



About Relapsing Polychondritis UK (RPUK)

All future references will be to RPUK.

RPUK is a Charitable Incorporated Organisation.

It is registered with the Charity Commission to operate in England, Wales and Scotland.

Registration number 1170936.

Date of registration 03/01/2017.

Address BRAYS ACCOUNTANTS
RIVERVIEW COURT
CASTLE GATE
WETHERBY
LS22 6LE

Telephone 01937 583043

Email info@relapsingpolychondritisuk.org

Legal purposes

The Objects of RPUK are:

The prevention and relief of sickness for the public benefit principally but not exclusively in the UK, among patients, healthcare professionals, researchers and other stakeholders affected by or wanting to work with any aspect of relapsing polychondritis by:

1. Educating the general public, those affected by relapsing polychondritis, their families and carers by the provision of information, advocacy and support
2. Supporting earlier diagnosis and greater access to treatment by increasing knowledge and awareness of relapsing polychondritis amongst healthcare professionals
3. Increasing understanding of the causes, treatment and potential cure of relapsing polychondritis by promoting and supporting research into all aspects of relapsing polychondritis and publishing the useful results of that research



Mission and aims

Mission Statement

To provide a unifying platform for those living with and working within the field of Relapsing Polychondritis; to raise awareness, increase knowledge and improve access to expertise and treatment.

We aim to:

- Provide reliably sourced information about RP
- Unite the RP community, giving you a voice

About relapsing polychondritis (RP)

The disease

RP is a rare disease affecting 3-5 individuals per million people. It affects both men and women with onset at any age from childhood through to later years, but most frequently in midlife.

It is thought to be an autoimmune disease. The body's immune system attacks its own cartilage and organs containing tissue similar to cartilage. Joints may become painful, swollen and stiff. The outer ear may become red, painful and deformed. Inflammation of the inner ear may result in nausea, hearing difficulties and loss of balance. The eyes may be affected, and vision may be impaired. Airways may become inflamed and/or collapse leading to coughing and/or breathing difficulties. The heart, blood vessels, liver and kidneys may be affected. Some patients develop skin rashes, head and/or nerve pain, which can be debilitating. Without prompt and effective treatment, RP can be lifethreatening and life-limiting.

Its impact

Before diagnosis

Because RP is a rare disease with no uniform presenting symptoms and no single diagnostic test, it is often misdiagnosed or diagnosed late - not uncommonly, several years after the onset of symptoms. By this time, the patient (and those close to the



patient) will have suffered emotionally and psychologically; the patient will have experienced prolonged pain and may have potentially avoidable but now irreversible physical damage; the patient and those close to the patient will be experiencing a consequent reduction in quality of life; relationships are under strain and many do not survive.

After diagnosis Clinicians

Because RP is a rare disease, many physicians will never have seen a case, and may have no knowledge of its effects or of the range of treatments available. They may never see another case. So, when NHS resources are under extreme pressure, rapid access to information and expertise would be valuable. Because RP can affect many of the body's systems (joints, ears, eyes, skin, nerves, airways, etc), this information needs to be available across medical specialties wherever patients may present.

Patients and carers

Patient experiences vary considerably depending on whether or not they live in an area where there are physicians with experience and knowledge of RP. Where this is lacking, patients and carers may have to wait longer and travel further at greater cost for appointments; it is likely that there will be fewer treatment options available to them.

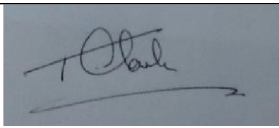

Accounts

This annual report accompanies accounts prepared in accordance with the Statement of Recommended Practice 'Charities SORP (FRS102)', applicable accounting standards, and the Charities Act 2011. RPUK does not have any employees. RPUK is operated entirely by volunteers. RPUK does not hold any funds as a custodian trustee. RPUK owns no property and its Trustees do not hold title to any property owned by RPUK.

Accounts cover the period 1/04/2022 – 31/03/2023.

They were approved by Jill Crossley on 22 January 2024.

This Annual Report was signed by:

Tina Clark		24/01/2024
Jill Crossley		24/01/2024



RPUK - ANNUAL PROGRESS REPORT

OBJECT

Educate the general public and those affected by relapsing polychondritis, their families and carers by the provision of information, advocacy and support

COMMENTS

Increase presence

Develop website.

Develop links to/from organisations that have developed information/websites.

Develop RP specific literature.

Attract funding

To ensure sustainability and make a difference over the longer term, RPUK reliably meets its running costs and continues to accumulate funds towards its development work. It, therefore, currently runs at a surplus.
RPUK receives both individual and regular donations both directly and through a variety of funding platforms.



Increase credibility

RPUK re-establish Clinical and Advisory Board with links to existing organisations

RPUK - ANNUAL PROGRESS REPORT

Increase understanding of the causes, treatment and potential cure of relapsing polychondritis by promoting and supporting research into all aspects of relapsing polychondritis and publishing the useful results of that research.

Establish:

- Links from/to other organisations with ongoing research
- A basic patient register accurately reflecting the population with RP
- A patient registry

RPUK is not yet funding research.

DONE

**ONGOING -
REASONABLE**

**ONGOING - WORK
NEEDED**

RPUK - ANNUAL PROGRESS REPORT

Governance

It is important that RPUK:

- abides by Charity Commission rules
- abides by its own governing document
- is transparent.

RPUK has had regard to the Charity Commission's guidance on public benefit (<https://www.gov.uk/government/publications/public-benefit-running-a-charity-pb2/public-benefitrunning-a-charity>)

Only Trustee personal contact details are withheld as previously authorised by the Charity Commission

Trustees

- RPUK must have a minimum of 3 and a maximum of 12 Trustees. If the number falls below 3, the remaining Trustee(s) may act only to call a meeting or appoint new Trustee(s). RPUK has no Chair.
- Throughout the reporting period 01/04/2022 to 31/03/2023, governors and Treasurer remained unchanged.

Clinical and Advisory Board

The following were appointed in June/July 2017 but are **now subject to review following Covid-19, changing roles and retirement.**

Professor Martin Birchall, Consultant in ENT Surgery

Professor David D'Cruz, Consultant Rheumatologist



Mrs Jemma Haines, Consultant Speech and Language Therapist
Dr James Hull, Consultant Respiratory Physician
Dr David Jayne, Honorary Consultant Physician
Dr Rob Niven, Consultant Respiratory Physician (now retired)

Policies

Finalise all appropriate policies.

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RELAPSING POLYCHONDritis UK (RPUK)

**CHARITY ACCOUNTS
FOR THE YEAR ENDED 31 MARCH 2023**



RELAPSING POLYCHONDritis UK (RPUK)

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RELAPSING POLYCHONDritis UK (RPUK)

CHARITY INFORMATION FOR THE YEAR ENDED 31 MARCH 2023

CHARITY REGISTRATION NUMBER	1170936
TRUSTEES ACTIVE DURING THE PERIOD	Tina Clark Jill Crossley Roy William Clark
TREASURER	Jonathan Crossley
REGISTERED ADDRESS	BRAYS Riverview Court Castle Gare Wetherby LS22 6LE
TELEPHONE	01937 583 043
EMAIL	info@relapsingpolychondritisuk.org

RELAPSING POLYCHONDritis UK (RPUK)

RECEIPTS & PAYMENTS SUMMARY FOR THE YEAR ENDED 31 MARCH 2023

	31 March 2023	31 March 2022
RECEIPTS		
Recurring donations	360.00	360.00
One-off donations	-	-
Online donation platforms	85.35	78.90
Gift Aid	<u>-</u>	<u>-</u>
TOTAL RECEIPTS	445.35	438.90
PAYMENTS		
Charity running costs	<u>284.63</u>	<u>403.27</u>
TOTAL PAYMENTS	(284.63)	(403.27)
SURPLUS OF RECEIPTS OVER PAYMENTS	<u>160.72</u>	<u>35.63</u>

RELAPSING POLYCHONDritis UK (RPUK)

BALANCE SHEET

FOR THE YEAR ENDED 31 MARCH 2023

	31 March 2023	31 March 2022
CURRENT ASSETS		
Current account	12,822.30	12,534.73
Gift aid claimed not yet paid	<u>-</u>	<u>126.85</u>
TOTAL ASSETS	12,822.30	12,661.58
CURRENT LIABILITIES		
Owed to trustees re expenses	<u>22.02</u>	<u>22.02</u>
TOTAL LIABILITIES	(22.02)	(22.02)
NET ASSETS	<u>12,800.28</u>	<u>12,639.56</u>
CHARITABLE RESERVES		
Reserves brought forward	12,639.56	12,603.93
Surplus for the year	<u>160.72</u>	<u>35.63</u>
RESERVES CARRIED FORWARD	<u>12,800.28</u>	<u>12,639.56</u>

Approved by the trustees on 22 January 2024 and signed on their behalf by:



Jill Crossley - Trustee

RELAPSING POLYCHONDritis UK (RPUK)

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2023

ACCOUNTING POLICIES

Basis of preparation

The accounts have been prepared under the historical cost convention and in accordance with the Statement of Recommended Practice 'Charities SORP (FRS 102)', applicable accounting standards and the Charities Act 2011.

Incoming resources

Voluntary income, including donations, which provide the core funding for the charity, is recognised where there is an entitlement, certainty of receipt, and the amount can be measured with sufficient reliability.

Incoming resources from tax reclaims are included in the receipts and payments summary at the same time as the gift to which they relate.

Resources expended

Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to the expenditure. All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs of a similar nature.

Taxation

As a registered charity, RPUK is generally exempt from Income Tax and Capital Gains Tax, but not from VAT. Irrecoverable VAT is included in the cost of those items to which they relate.

Gift Aid is reclaimed by the charity on donations from individuals from whom the charity has received a signed gift aid declaration.