



Trustees' Annual Report for the period						
Period start date			Period end date			
Day	Month	Year	Day	Month	Year	
01	April	2024	31	March	2025	
From			To			

Section A Reference and administration details

Charity name	Ring20 Research and Support UK CIO
Other names charity is known by	
Registered charity number (if any)	1165651
Charity's principal address	Lytchett House, 13 Freeland Park Wareham Road Poole, Dorset BH16 6FA

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Lydia Hirst	Chairperson		
2	Kim Parks	Treasurer		
3	Dale Ward	Patient Representative		
4	Tim Buckinx	Patient Representative		
5	Clara Tang	Research		
6	Antonio Gil-Nagel	Chief Medical Advisor		

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

Allison Watson – CEO

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	CIO association constitution
How the charity is constituted (eg. trust, association, company)	CIO association constitution (formed 19 February 2016)
Trustee selection methods (eg. appointed by, elected by)	By appointment of registered members at general meetings and by Trustees

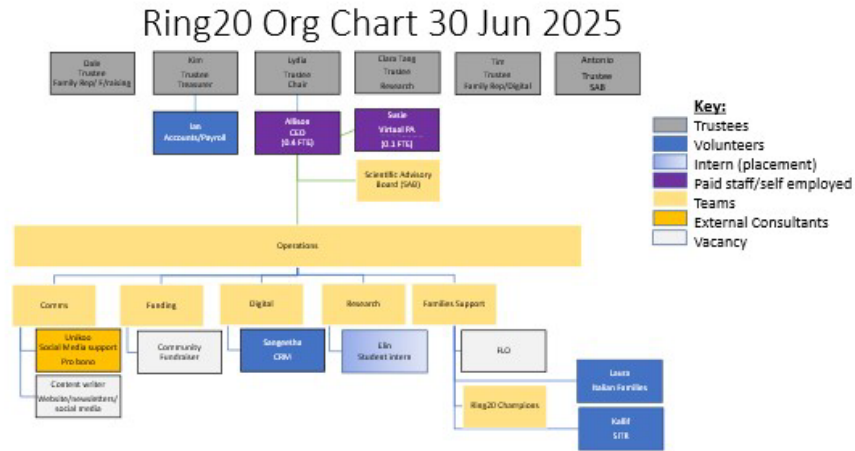
Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

Susie Inman acts as Secretary to the Board of Trustees.

Ring20 continues to operate with one part-time member of staff (CEO, Allison Watson, 0.4 FTE) supported by a committed group of volunteers and student placements. External consultants are also engaged as required.



Our CEO also volunteers an equivalent amount of unpaid time and oversees all operational areas, including family support, research, communications, and volunteer management.

The Board of Trustees meets regularly to review strategic priorities and governance, supported by an International Scientific Advisory Board (SAB) of clinicians and researchers from multiple disciplines and countries. New Trustees are expected to abide by a Code of Conduct, sign a Trustee Declaration Form and a Fit and Proper Persons Form. DBS checks are also carried out.

The SAB is chaired by Dr Antonio Gil-Nagel, Associate Head of Neurology at Ruber International Hospital in Madrid, Spain and is made up of 16 other healthcare researchers and scientists.

Ring20 collaborates extensively with partners across the rare disease and neurological sectors to maximise impact and ensure the voice of our community is represented nationally and internationally. The charity is a member of the following networks:

- Genetic Alliance UK (GAUK): CEO sits on Patient Advisory Group (inputting to the England Rare Diseases Action plan) and UK Patient Empowerment Group (PEG)
- Neurological Alliance, England: CEO represents Ring20 in the Rare Disease sub-group
- CamRARE: CEO attends Companies Forum (2x p.a.) as a Patient Advocacy Group representative and also supports CamRARE/PLRH in developing the Rare Disease Research Network (RDRN) platform
- International Bureau for Epilepsy (IBE) – UK chapter
- EURORDIS, RC NET/RareQOL, Rare Revolution, Rare Epilepsy Network (REN), NCVO

The CEO is also founder of the UK Rare Epilepsies Together (UKRET) network, bringing together charities supporting families affected by rare epilepsies across the UK to improve service delivery across the NHS and drive research.

Summary of the objects of the charity set out in its governing document

The objects of the charity are the advancement of health and the relief of disability, by providing support and information to individuals, families, and health professionals affected by Ring Chromosome 20 Syndrome (r(20)), an ultra-rare epilepsy syndrome causing drug-resistant seizures and cognitive challenges.

Ring20 Research and Support UK is the only charity dedicated to people living with Ring Chromosome 20 Syndrome (r(20)). It was founded by families, for families, with a simple mission: **to ensure no one faces Ring20 alone**—and to accelerate the research that leads to earlier diagnosis, better treatment, and improved quality of life.

The charity raises funds to help promote research into r(20) with the aim of improving overall quality of life for those living with the disease.

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

Ring chromosome 20 syndrome [r(20)] is a rare epilepsy syndrome with case numbers likely to be under-reported worldwide due to lack of awareness of the signs and symptoms and under-diagnosis.

How the charity helps:

- Provides Services
- Provides Advocacy/advice/information

Trustees confirm they have had due regard to the Charity Commission's guidance on public benefit in planning and delivering the charity's activities.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

The Ring20 Trustees would like to thank our volunteers for their support throughout the year.

Special mention should go to our key volunteers during the period:

- Belinda Hunt (Bid Writing)
- Ian Allen (Accounts/Payroll)
- Kallif Garlicki (Step Into The Ring)
- Laura Giordana (Italian families support)

Several of our family members act as Ring20 Champions, meeting regularly helping to connect families in their own countries/languages.

- Dale Ward (UK)
- Yvonne Goodson (UK)
- Andre Reis e Silva (Portugal)
- Steve Baumley (USA)
- Junko Okuda (USA/Japan)
- Tim Buckinx (Belgium/Netherlands)
- Arantxa Miralles (Spain)

Thanks also go to those who provided pro bono support during the year:

- Unikoo (formerly BlueZoo): helping to schedule our social media

Summary of the main achievements of the charity during the year

Families Support / Information Services

During 2024–25, Ring20 continued to be a vital source of information, connection, and emotional support for families living with r(20) worldwide.

We reached families in over 20 countries and supported more than 160 family members through peer-to-peer contact, social media engagement, and regular online meetings.

Our **peer support network**—including our Ring20 Champions—played a pivotal role in helping families navigate the challenges of daily life with r(20). Champions offered one-to-one contact, facilitated introductions between new and existing members, and supported translation of resources into multiple languages, ensuring inclusivity across our global community.

We delivered **online “Coffee and Chat” sessions** and dedicated **“Step Into the Ring” peer meetings** for adults living with r(20). These safe and supportive spaces allowed participants to share experiences, reduce isolation, and build confidence in managing their condition. Feedback consistently highlights the value of these sessions in helping families feel heard and less alone.

Our **website and digital channels** remain the central hub for reliable information on r(20). Content is automatically translated into nine languages, extending our reach to clinicians and families worldwide. Updates are shared regularly through e-newsletters and social media, helping to raise awareness among healthcare professionals and the public alike.

Ring20 continues to provide **direct one-to-one support** to families by phone, email, and video calls, offering guidance on clinical care, education, and emotional wellbeing. Families often tell us that we are “the only organisation that truly understands” their situation.

This year, we also began planning for the launch of a **Family Liaison Pilot**, aiming to offer a single trusted point of contact for families seeking personalised advice on education, health, and social care. This initiative, dependent on future funding, will strengthen our support model and ensure consistency of care for newly diagnosed families.

Promoting Opportunities for, and Participating in Research

Our research activities are directly informed by the lived experiences of families, ensuring that future studies address the most pressing challenges faced by those affected by r(20).”

We continued to build on the success of the 2024 “Impact of Living with Ring Chromosome 20 Syndrome” study, using findings to shape policy discussions and awareness campaigns.

Our collaboration with clinicians, academic researchers, and genomic partners such as Illumina are helping to advance understanding of structural chromosomal abnormalities often missed by standard genetic testing.

We actively contributed to sector-wide meetings, including the Rare Disease Research Network, and engaged in discussions to improve clinical recognition and pathways for diagnosis.

Training and Mentoring

Our CEO participated in leadership training and mentoring programmes through Beacon for Rare Diseases to strengthen our impact across research and policy arenas, including the Decoding Diagnostics, Mentoring Programme, and Patient Group Pathway.

These initiatives strengthened our advocacy capacity and built our skills for engaging effectively across the research and healthcare landscape.

Ring20 also hosted and mentored university placement students from Aston University, who supported our outreach efforts.

Achievements in Research, Advocacy and Education

Throughout 2024–25, Ring20 built new alliances and strengthened relationships across the rare-disease ecosystem — participating in key events and collaborative networks to amplify the voices of families affected by r(20).

These partnerships are essential in driving change — from clinical recognition to policy advocacy.

During the year, Ring20 engaged widely across the sector, presenting, attending, and contributing to multiple events, meetings, and collaborations.

We presented at:

- Aspire Biosciences Rare Neurology / CNS Partnering Cohort
- RAREfest24
- World Orphan Drug Congress
- British Paediatric Neurology Annual Conference
- Rare Disease Research UK co-production webinar

We represented Ring20 at:

- Young Epilepsy / Epilepsy Research Institute (May 2024)
- EDIRA Building Trust Symposium (June 2024)
- BPNA Stakeholder Engagement Meeting (Sept 2024)
- UKRET Challenges to Diagnosis, Treatment and Care Roundtable (Sept 2024)
- UKRET Solutions to Diagnosis, Treatment and Care Roundtable (Mar 2024)
- PPP Rare Disease Insights Report Launch (Nov 2024)
- Festival of Genomics (Jan 2025)
- Rare Disease Day Parliamentary Reception (Feb 2025)

We contributed to meetings and workshops as a Patient Advocacy Expert at:

- CamRARE Companies Forum (May & Dec 2024)
- Genetic Alliance UK Rare Disease Patient Advisory Group (PAG) – including input to the NHS 10-Year Plan
- UK Rare Disease Patient Empowerment Group (PEG) – including input to the Quality Standard on Rare Conditions
- Rare Disease Research Network
- UCB Hosted Patient Organisation Day
- DHSC Rare Disease Workshop
- UCB Rare Epilepsies Workshop
- Rare Disease Individualised Therapies System Information Day
- Gene People Symposium
- AMRC & Genetic Alliance 10-Year Plan for Health Workshop

Section D

Achievements and performance

- Patient Engagement (for Genomics England)
- CREA / E+

We engaged with Pharma & industry:

- LifeArc
- Oxford Nanopore
- Lundbeck
- Aparito
- Acadia
- PacBio
- Mendelian
- UCB

Through these activities, Ring20 has continued to raise awareness of r(20) across scientific, clinical, and policy arenas, positioning the charity as a key voice in rare epilepsy advocacy.

Leadership

Our CEO founded and leads the UK Rare Epilepsies Together (UKRET) network and represented Ring20 and UKRET during the:

- NICE HTA appeal process for Fenfluramine, successfully contributing to its approval for Lennox–Gastaut Syndrome — a meaningful outcome for the rare epilepsy community.
- Both The Challenges and the Solutions Roundtables building: A Case for Change for Rare and Complex Epilepsies in the UK

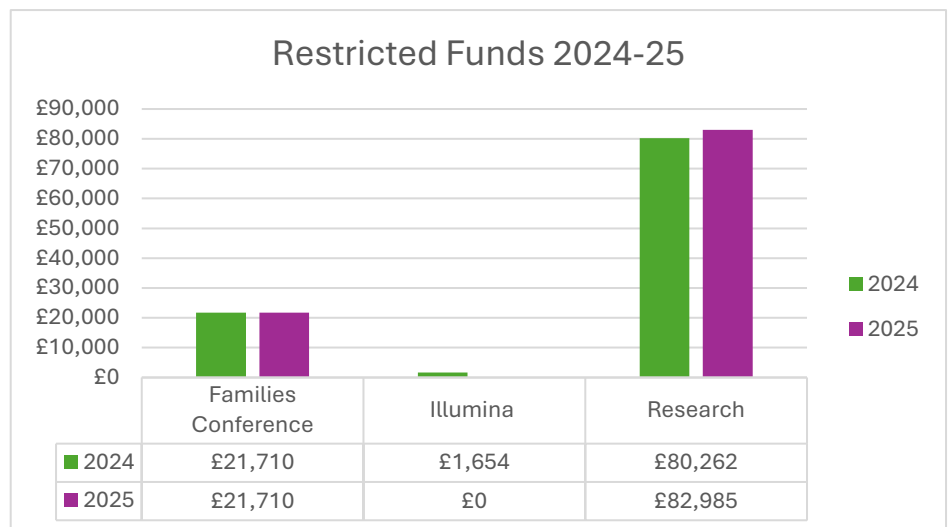
Section E

Financial review

Brief statement of the charity's policy on reserves

The charity maintains restricted funds dedicated to specific projects, including family support and research activities.

Our restricted funds currently total £104,695 comprised as follows:



We are currently evaluating applications for our Research Fund following an Open Call offering a grant of up to £80,000 to be awarded for innovative research into r(20) syndrome.

We plan to use our Families Conference fund towards the delivery of an event for families in Q3 2026.

General reserves are held in cash to ensure operational stability and cover unforeseen events.

The trustees aim to hold reserves sufficient to cover approximately six months of operating costs.

The general reserves are the unspent unrestricted funds of the charity. The charity currently owns no fixed assets, so the general reserve is held in cash. The general reserve is therefore the free reserves of the charity **plus any designated funds**, also termed 'unrestricted funds' in the charity's balance sheet. The purpose of the general reserve is:

- ☐ To fund working capital and time lags in the receipt of promised funds
- To fund unexpected expenditure, e.g., when projects overrun, or unplanned events occur
- Manage economic or regulatory changes which may have unforeseen financial consequences

We assess the level of general reserve needed by looking forward and considering the risks to our funding balanced against our expenditure commitments. Future plans show levels of committed expenditure for which we are seeking funding, but to ensure we can continue to operate in accordance with our plans, we hold free reserves in the range £10,000 - £12,000 to cover unfunded committed costs for 6 months.

General Reserves before funds designated	£	45,178
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Designated Funds towards next financial year 2025-26

Personnel

Salaries (6 months)	£	8,623
Family Liaison Officer	£	6,000
Virtual Assistant	£	2,500
Bid Writer	£	6,000

Other Expenditure

Events	£	2,500
CRM	£	1,200
Overheads (6 months)	£	1,717
FLO Costs	£	3,000

TOTAL FREE RESERVES	£	13,639
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Our general reserve as at 31 March 2025 was £45,178 (of which £31,539 has been designated as above) leaving £13,639 of Free Reserves, which is a little more than the reserves policy recommends.

Details of any funds materially in deficit

n/a

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

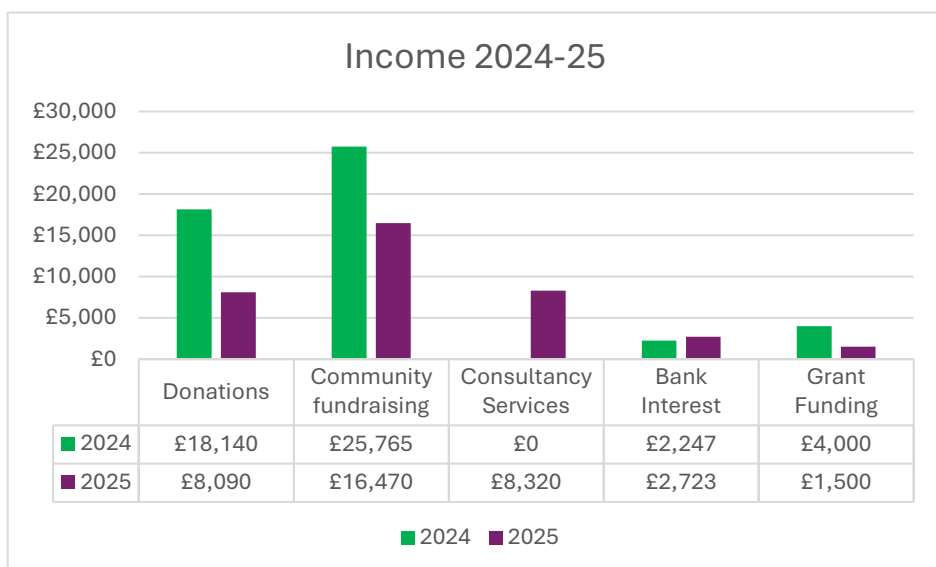
- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

Income

Our income reflects a strong year of community engagement and collaboration, with a continued focus on diversifying our funding streams including the introduction of consultancy services.

Year on year donations and community fundraising are lower, reflecting the impact of the cost-of-living crisis on individual giving. The widely reported significant rise in grant requests received by Trusts and Foundations due to the current economic situation and the influx of AI applications has impacted on our ability to secure funds via this revenue stream, despite our increased efforts.

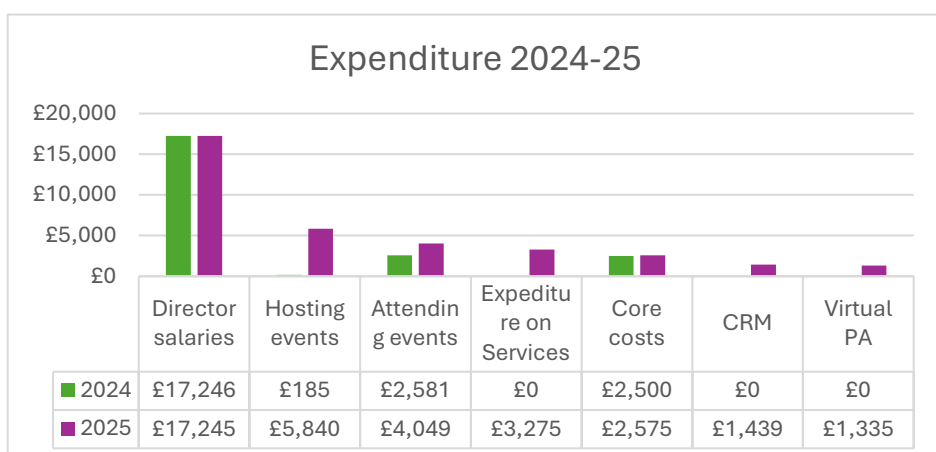
During the financial year ending 31 March 2025, Ring20 generated income of £37,103, comprised of:



Expenditure

To mitigate against lower revenue generation, we invested in a CRM and Virtual PA increasing capacity to allow us to continue to deliver services.

During the financial year ending 31 March 2025, Ring20 expenditure totaled £35,758 comprised of:



Section F

Other optional information

Looking Ahead

In 2025–26, Ring20 aims to expand peer support services, strengthen research collaborations, and secure additional funds to launch our Family Liaison Pilot, ensuring that every person affected by r(20) has access to the information, care, and connection they need.

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)

	
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Full name(s)

Lydia Hirst	Kim Parks
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Position (eg Secretary, Chair, etc)




Chair	Treasurer
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Date

28 / 11 / 2025

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