

# RING20 RESEARCH AND SUPPORT UK CIO

England & Wales · Charity number 1165651

## Details

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**Status** Registered

**Legal form** CIO

**Registered** 2016-02-19

**Register** [View on the Charity Commission register](#)

## Contact

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**Address** Lytchett House  
Unit 13 Freeland Park  
Wareham Road  
Poole  
Dorset  
BH16 6FA

**Phone** +44 (0)7385 292797

**Email** [ring20@ring20researchsupport.co.uk](mailto:ring20@ring20researchsupport.co.uk)

**Website** <http://www.ring20researchsupport.co.uk/>

## Activities

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**Objects:** "THE OBJECTS OF THE CIO ARE: THE PRESERVATION AND PROTECTION OF HEALTH AND THE RELIEF OF NEED IN PARTICULAR BY:A) PROVIDING ADVICE, SUPPORT AND INFORMATION TO RING CHROMOSOME 20 SYNDROME (R)20 PATIENTS AND THEIR FAMILIES;B) PROVIDING OR ASSISTING IN THE PROVISION OF INFORMATION TO THE PUBLIC ABOUT THE CONDITION (R)20;C) SUPPORTING MEDICAL PROFESSIONALS IN THEIR UNDERSTANDING OF RING CHROMOSOME 20 SYNDROME, (R)20 ITS DIAGNOSIS, PROGNOSIS AND TREATMENT;D) SUPPORTING RESEARCH INTO THE CONDITION, (R)20, ITS CAUSES AND THE MEANS TO IMPROVE THE OUTCOMES FOR THOSE SUFFERING WITH THE CONDITION AND PROMOTING THE DISSEMINATION OF THE USEFUL RESULTS OF SUCH RESEARCH.

**Activities:** We provide support and information to individuals, families and health professionals who are affected by, or come into contact with Ring Chromosome 20 Syndrome, or r(20) for short, an ultra-rare disease, the main symptom being difficult to treat epilepsy. We raise funds to help promote research into r(20) to try to improve overall quality of life for those living with the disease.

## Classification

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- **How:** Provides Services, Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities

## Geography

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- Northern Ireland
- Scotland
- Throughout England And Wales

## Finances

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Period end	Income	Expenditure	Assets	Employees
2025-03-31	£37,103	£35,758	-	-
2024-03-31	£50,152	£23,341	-	-
2023-03-31	£40,340	£45,324	-	-
2022-03-31	£40,476	£32,453	-	-
2021-03-31	£43,839	£12,779	-	-

## Trustees

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Name	Role	Appointed
<b>Lydia Elena Hirst</b>	Chair	2020-11-01
Dale Ward		2021-12-03
Dr Antonio Gil-Nagel		2024-04-17
Dr Sze-Man Clara Tang		2024-11-24
Kim Parks		2020-10-01
Tim Buckinx		2022-11-27

**RING20 RESEARCH AND SUPPORT UK CIO**

England & Wales - Charity number 1165651

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# Accounts

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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
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## 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

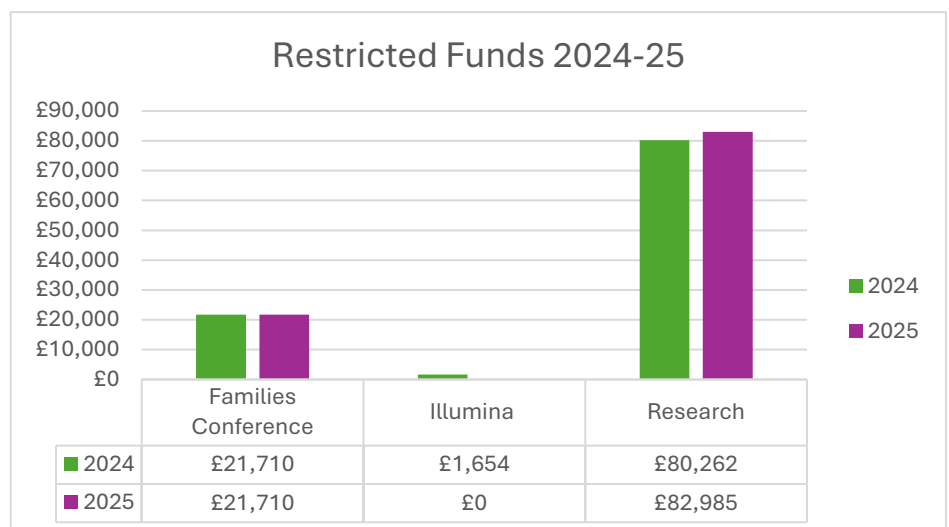
## Section E

## 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.

<b>General Reserves before funds designated</b>	<b>£</b>	<b>45,178</b>
 <i>Designated Funds towards next financial year 2025-26</i>		
<i>Personnel</i>		
Salaries (6 months)	£	8,623
Family Liaison Officer	£	6,000
Virtual Assistant	£	2,500
Bid Writer	£	6,000
<i>Other Expenditure</i>		
Events	£	2,500
CRM	£	1,200
Overheads (6 months)	£	1,717
FLO Costs	£	3,000
 <b>TOTAL FREE RESERVES</b>	 <b>£</b>	 <b>13,639</b>

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:

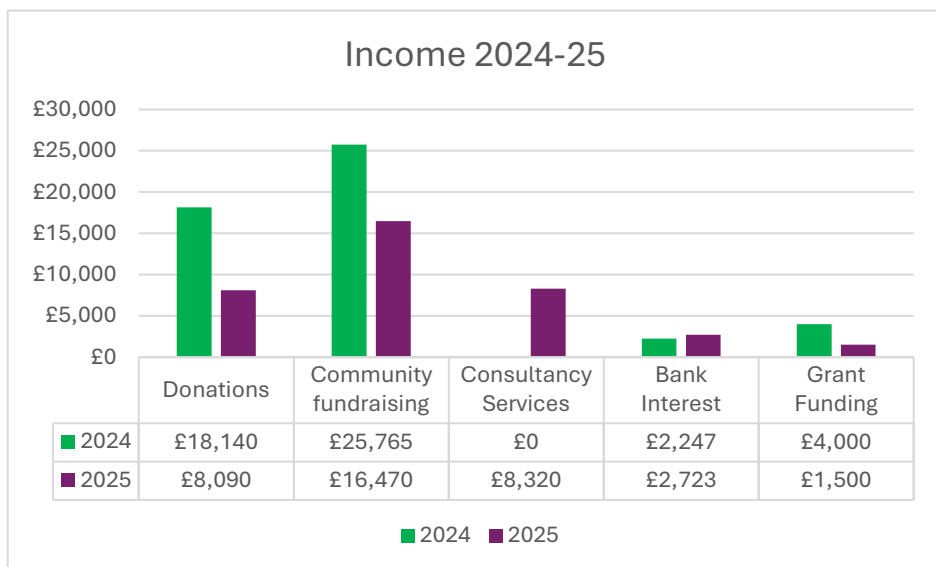
- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

### 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.

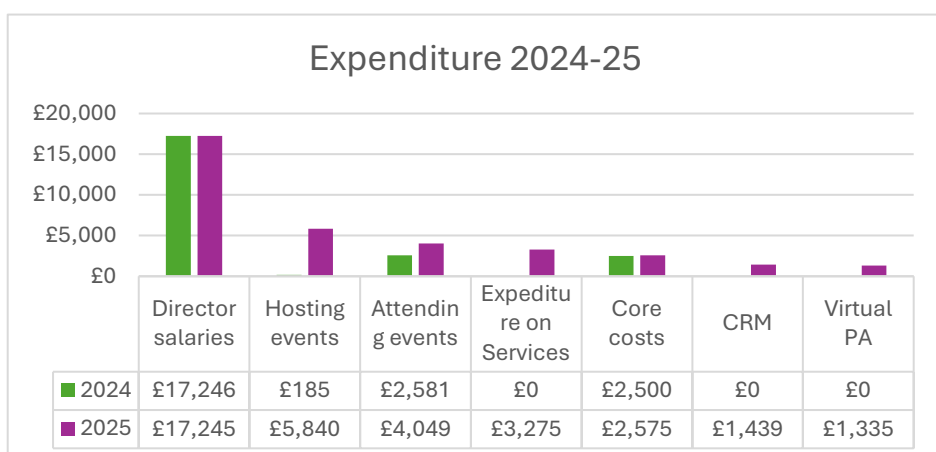
During the financial year ending 31 March 2025, Ring20 generated income of £37,103, comprised of:



### 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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Title	Ring20 Trustee Report
File name	Ring20_Annual_Tru...2024-25_FINAL.pdf
Document ID	f9125e5b3709f9c343aa95b98951b4b4c1d3609c
Audit trail date format	DD / MM / YYYY
Status	● Signed

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## Document history

 SENT	<b>28 / 11 / 2025</b> 11:28:53 UTC	Sent for signature to Kim Parks (kim@parksbookkeeping.co.uk) and Lydia Hirst (lydia@ring20researchsupport.co.uk) from allison@ring20researchsupport.co.uk IP: 95.145.34.45
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 COMPLETED	<b>28 / 11 / 2025</b> 13:41:59 UTC	The document has been completed.

**RING20 RESEARCH AND SUPPORT UK CIO**

Charity number 1165651

**FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31st MARCH 2025**

# RING20 RESEARCH AND SUPPORT UK CIO

## CONTENTS FOR THE YEAR ENDED 31 MARCH 2025

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Independent examiner's report	5

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# RING20 RESEARCH AND SUPPORT UK CIO

## STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 MARCH 2025

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	Note	Unrestricted Fund £	Restricted Fund £	2025 Total £
<b>Incoming resources from charitable activities:</b>				
Donations and legacies	2	2,797	5,293	8,090
Charitable activities	3	24,243	4,770	29,012
<b>Total income</b>		<b>27,040</b>	<b>10,063</b>	<b>37,103</b>
<b>Resources expended</b>				
<b>Charitable payments</b>				
Charitable activities	4	28,409	7,349	35,758
Fundraising expenditure		-	-	-
<b>Total expenditure</b>		<b>28,409</b>	<b>7,349</b>	<b>35,758</b>
<b>Net receipts/(payments)</b>		<b>(1,369)</b>	<b>2,714</b>	<b>1,344</b>
<b>Transfer between funds</b>		1,645	(1,645)	-
<b>Change in accounting policy</b>		(248)	-	(248)
<b>Net of receipts/(payments)</b>		<b>28</b>	<b>1,069</b>	<b>1,096</b>
<b>Cash funds brought forward</b>	5	45,151	103,626	148,777
<b>Cash funds carried forward</b>	5	<b>45,179</b>	<b>104,695</b>	<b>149,873</b>

The notes on page 3 - 4 form part of these accounts

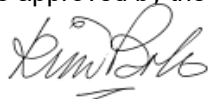
# RING20 RESEARCH AND SUPPORT UK CIO

## BALANCE SHEET AS AT 31 MARCH 2025

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	Notes	2025 £
<b><u>Current assets</u></b>		
Cash at bank and in hand		143,996
Debtors	5	8,398
		<u>152,394</u>
<b><u>Current liabilities</u></b>		
Creditors	6	2,521
	6	-
		<u>2,521</u>
<b>Total assets less liabilities</b>		<u><u>149,873</u></u>
<b><u>Represented by</u></b>		
Unrestricted funds	5	45,179
Restricted funds	5	104,695
		<u><u>149,873</u></u>

These accounts were approved by the Trustees, and signed on their behalf by:

Trustee:  \_\_\_\_\_

Date: 28/11/2025

Name: Kim Parks

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025

### 1. Accounting policies

#### Basis of the preparation of the accounts

From this financial period, the accounts have been completed on an accruals basis. Previously the accounts were prepared on a cash basis. The change in accounting policy has been made by the trustees to better reflect the financials for each year. As a result of the change of policy, there are no comparative figures for the year ended 31 March 2025.

#### Incoming resources

All material incoming resources have been included on a receivable basis i.e. they are included if the date receivable falls within the period covered by these accounts.

#### Resources expended

These have been analysed using a natural classification.

#### Going Concern

The charity is operating on a going concern basis.

### 2. Donations

	Unrestricted Fund £	Restricted Fund £	Total 2025 £	Total 2024 £
General donations	2,797	5,293	8,090	18,140
	<u>2,797</u>	<u>5,293</u>	<u>8,090</u>	<u>18,140</u>

### 3. Charitable Activities

	Unrestricted Fund £	Restricted Fund £	Total 2025 £	Total 2024 £
Grant funding	-	1,500	1,500	4,000
Member fundraising	16,470	-	16,470	25,765
Services income	7,773	547	8,320	-
Bank interest received	-	2,723	2,723	2,247
	<u>24,243</u>	<u>4,770</u>	<u>29,012</u>	<u>32,012</u>

### 4. Expenditure from charitable activities

	Unrestricted Fund £	Restricted Fund £	Total 2025 £	Total 2024 £
Attending conferences & events	655	849	1,504	2,581
Hosting conferences & events	1,885	6,500	8,385	185
Cost of sales	3,275	-	3,275	-
Literature & materials	77	-	77	189
Website & emails	197	-	197	374
Accountancy, examination & audit	680	-	680	250
Director salaries	17,245	-	17,245	17,246
Wages & salaries	1,335	-	1,335	-
Office expenditure	199	-	199	353
Bank charges	87	-	87	95
Computer costs	1,623	-	1,623	219
Insurances	374	-	374	360
Postage	115	-	115	109
Subscriptions	333	-	333	277
Telephone	300	-	300	199
Training & DBS costs	30	-	30	75
	<u>28,409</u>	<u>7,349</u>	<u>35,758</u>	<u>22,512</u>

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025

<b>5. Debtors</b>					<b>Total 2025 £</b>
Trade Debtors					8,398
					<b>8,398</b>
<b>6. Creditors</b>					<b>Total 2025 £</b>
Accruals					3,615
Taxes and Social Security					- 1,094
					<b>2,521</b>
<b>4. Funds analysis</b>	<b>Balance at 01/04/25 £</b>	<b>Incoming Funds £</b>	<b>Expended Funds £</b>	<b>Transfers in/out £</b>	<b>Balance at 31/03/25 £</b>
<b>Unrestricted</b>					
Running costs	28,832	10,570	(8,412)	(2,281)	<b>28,709</b>
Fundraising	-	16,470	-	-	<b>16,470</b>
<b>Designated funds</b>					
Salaries	13,319	-	(17,245)	3,926	-
Overheads	3,000	-	(3,000)	-	-
	<b>45,151</b>	<b>27,040</b>	<b>(28,657)</b>	<b>1,645</b>	<b>45,179</b>
<b>Restricted funds</b>					
Family Conference	21,710	-	-	-	<b>21,710</b>
Illumina Research Project	1,654	-	-	(1,654)	-
Research Funds	80,262	2,723	-	-	<b>82,985</b>
Race Day	-	5,840	(5,840)	-	-
Info Materials	-	1,500	(1,509)	9	-
<b>Total restricted funds</b>	<b>103,626</b>	<b>10,063</b>	<b>(7,349)</b>	<b>(1,645)</b>	<b>104,695</b>
<b>Totals</b>	<b>148,777</b>	<b>37,103</b>	<b>(36,006)</b>	<b>-</b>	<b>149,874</b>

### 5. Trustee payments

During the previous financial year, one trustee was remunerated £17,246 as wages during the year. This trustee resigned on the January 2024, and therefore the amount detailed as trustee payments is Nil for this financial year.

### 6. Related party transactions

There were no related party transactions during the year.

### 7. Key management personnel

No staff have earned more than £60,000 during the year.

# RING20 RESEARCH AND SUPPORT UK CIO

## INDEPENDENT EXAMINER'S REPORT FOR THE YEAR ENDED 31 MARCH 2025

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I report on the accounts of Ring20 Research and Support UK CIO for the year ended 31 March 2025 which are set out on pages 1 to 4.

### **Respective responsibilities of trustees and examiner**

The Charity's Trustees are responsible for the preparation of the accounts. The Charity's Trustees consider that an audit is not required for this year (under section 144 (2) of the Charities Act 2011 (The Act) but that an independent examination is needed.

It is my responsibility to:

- Examine the accounts under section 145 of the Charities Act,
- To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 145(5)(b) of the Charities Act, and
- To state whether particular matters have come to my attention.

### **Basis of independent examiner's Statement**

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the Charity and a comparison of the accounts presented with those records. It also includes considerations of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently I do not express an audit opinion on the view given by the accounts.

### **Independent examiner's statement**

In the course of my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of the accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair' view which is not a matter considered as part of an independent examination.

I have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

David Courtier FMAAT AATQB for and on behalf of:

Community360



Winsley's House, High Street, Colchester, Essex

Date: 28/11/2025

# **RING20 RESEARCH AND SUPPORT UK CIO**

Charity number 1165651

**FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31st MARCH 2025**

# RING20 RESEARCH AND SUPPORT UK CIO

## CONTENTS FOR THE YEAR ENDED 31 MARCH 2025

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	Page
Statement of financial activities	1
Balance Sheet	2
Notes to the financial statements	3-4
Independent examiner's report	5

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# RING20 RESEARCH AND SUPPORT UK CIO

## STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 MARCH 2025

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	Note	Unrestricted Fund £	Restricted Fund £	2025 Total £
<b>Incoming resources from charitable activities:</b>				
Donations and legacies	2	2,797	5,293	8,090
Charitable activities	3	24,243	4,770	29,012
<b>Total income</b>		<b>27,040</b>	<b>10,063</b>	<b>37,103</b>
<b>Resources expended</b>				
<b>Charitable payments</b>				
Charitable activities	4	28,409	7,349	35,758
Fundraising expenditure		-	-	-
<b>Total expenditure</b>		<b>28,409</b>	<b>7,349</b>	<b>35,758</b>
<b>Net receipts/(payments)</b>		<b>(1,369)</b>	<b>2,714</b>	<b>1,344</b>
<b>Transfer between funds</b>		1,645	(1,645)	-
<b>Change in accounting policy</b>		(248)	-	(248)
<b>Net of receipts/(payments)</b>		<b>28</b>	<b>1,069</b>	<b>1,096</b>
<b>Cash funds brought forward</b>	5	45,151	103,626	148,777
<b>Cash funds carried forward</b>	5	<b>45,179</b>	<b>104,695</b>	<b>149,873</b>

The notes on page 3 - 4 form part of these accounts

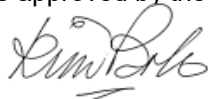
# RING20 RESEARCH AND SUPPORT UK CIO

## BALANCE SHEET AS AT 31 MARCH 2025

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	Notes	2025 £
<b><u>Current assets</u></b>		
Cash at bank and in hand		143,996
Debtors	5	8,398
		<u>152,394</u>
<b><u>Current liabilities</u></b>		
Creditors	6	2,521
	6	-
		<u>2,521</u>
<b>Total assets less liabilities</b>		<u><u>149,873</u></u>
<b><u>Represented by</u></b>		
Unrestricted funds	5	45,179
Restricted funds	5	104,695
		<u><u>149,873</u></u>

These accounts were approved by the Trustees, and signed on their behalf by:

Trustee:  \_\_\_\_\_

Date: 28/11/2025

Name: Kim Parks

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025

### 1. Accounting policies

#### Basis of the preparation of the accounts

From this financial period, the accounts have been completed on an accruals basis. Previously the accounts were prepared on a cash basis. The change in accounting policy has been made by the trustees to better reflect the financials for each year. As a result of the change of policy, there are no comparative figures for the year ended 31 March 2025.

#### Incoming resources

All material incoming resources have been included on a receivable basis i.e. they are included if the date receivable falls within the period covered by these accounts.

#### Resources expended

These have been analysed using a natural classification.

#### Going Concern

The charity is operating on a going concern basis.

### 2. Donations

	Unrestricted Fund £	Restricted Fund £	Total 2025 £	Total 2024 £
General donations	2,797	5,293	8,090	18,140
	<u>2,797</u>	<u>5,293</u>	<u>8,090</u>	<u>18,140</u>

### 3. Charitable Activities

	Unrestricted Fund £	Restricted Fund £	Total 2025 £	Total 2024 £
Grant funding	-	1,500	1,500	4,000
Member fundraising	16,470	-	16,470	25,765
Services income	7,773	547	8,320	-
Bank interest received	-	2,723	2,723	2,247
	<u>24,243</u>	<u>4,770</u>	<u>29,012</u>	<u>32,012</u>

### 4. Expenditure from charitable activities

	Unrestricted Fund £	Restricted Fund £	Total 2025 £	Total 2024 £
Attending conferences & events	655	849	1,504	2,581
Hosting conferences & events	1,885	6,500	8,385	185
Cost of sales	3,275	-	3,275	-
Literature & materials	77	-	77	189
Website & emails	197	-	197	374
Accountancy, examination & audit	680	-	680	250
Director salaries	17,245	-	17,245	17,246
Wages & salaries	1,335	-	1,335	-
Office expenditure	199	-	199	353
Bank charges	87	-	87	95
Computer costs	1,623	-	1,623	219
Insurances	374	-	374	360
Postage	115	-	115	109
Subscriptions	333	-	333	277
Telephone	300	-	300	199
Training & DBS costs	30	-	30	75
	<u>28,409</u>	<u>7,349</u>	<u>35,758</u>	<u>22,512</u>

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025

<b>5. Debtors</b>					<b>Total 2025 £</b>
Trade Debtors					8,398
					<b>8,398</b>
<b>6. Creditors</b>					<b>Total 2025 £</b>
Accruals					3,615
Taxes and Social Security					- 1,094
					<b>2,521</b>
<b>4. Funds analysis</b>	<b>Balance at 01/04/25 £</b>	<b>Incoming Funds £</b>	<b>Expended Funds £</b>	<b>Transfers in/out £</b>	<b>Balance at 31/03/25 £</b>
<b>Unrestricted</b>					
Running costs	28,832	10,570	(8,412)	(2,281)	<b>28,709</b>
Fundraising	-	16,470	-	-	<b>16,470</b>
<b>Designated funds</b>					
Salaries	13,319	-	(17,245)	3,926	-
Overheads	3,000	-	(3,000)	-	-
	<b>45,151</b>	<b>27,040</b>	<b>(28,657)</b>	<b>1,645</b>	<b>45,179</b>
<b>Restricted funds</b>					
Family Conference	21,710	-	-	-	<b>21,710</b>
Illumina Research Project	1,654	-	-	(1,654)	-
Research Funds	80,262	2,723	-	-	<b>82,985</b>
Race Day	-	5,840	(5,840)	-	-
Info Materials	-	1,500	(1,509)	9	-
<b>Total restricted funds</b>	<b>103,626</b>	<b>10,063</b>	<b>(7,349)</b>	<b>(1,645)</b>	<b>104,695</b>
<b>Totals</b>	<b>148,777</b>	<b>37,103</b>	<b>(36,006)</b>	<b>-</b>	<b>149,874</b>

### 5. Trustee payments

During the previous financial year, one trustee was remunerated £17,246 as wages during the year. This trustee resigned on the January 2024, and therefore the amount detailed as trustee payments is Nil for this financial year.

### 6. Related party transactions

There were no related party transactions during the year.

### 7. Key management personnel

No staff have earned more than £60,000 during the year.

# RING20 RESEARCH AND SUPPORT UK CIO

## INDEPENDENT EXAMINER'S REPORT FOR THE YEAR ENDED 31 MARCH 2025

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I report on the accounts of Ring20 Research and Support UK CIO for the year ended 31 March 2025 which are set out on pages 1 to 4.

### **Respective responsibilities of trustees and examiner**

The Charity's Trustees are responsible for the preparation of the accounts. The Charity's Trustees consider that an audit is not required for this year (under section 144 (2) of the Charities Act 2011 (The Act) but that an independent examination is needed.

It is my responsibility to:

- Examine the accounts under section 145 of the Charities Act,
- To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 145(5)(b) of the Charities Act, and
- To state whether particular matters have come to my attention.

### **Basis of independent examiner's Statement**

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the Charity and a comparison of the accounts presented with those records. It also includes considerations of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently I do not express an audit opinion on the view given by the accounts.

### **Independent examiner's statement**

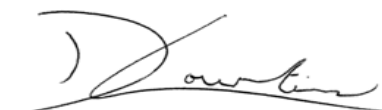
In the course of my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of the accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair' view which is not a matter considered as part of an independent examination.

I have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

David Courtier FMAAT AATQB for and on behalf of:

Community360



Winsley's House, High Street, Colchester, Essex

Date: 28/11/2025

**RING20 RESEARCH AND SUPPORT UK CIO**

England & Wales - Charity number 1165651

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# Accounts

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Trustees' Annual Report for the period						
Period start date			Period end date			
Day	Month	Year	Day	Month	Year	
01	April	2023	31	March	2024	
From			To			

## Section A Reference and administration details

Charity name

Other names charity is known by

Registered charity number (if any)

Charity's principal address

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	Allison Watson	CEO/Secretary		
3	Kim Parks	Treasurer		
4	Dale Ward	Patient Representative		
5	Tim Buckinx	Patient Representative		

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)

## 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

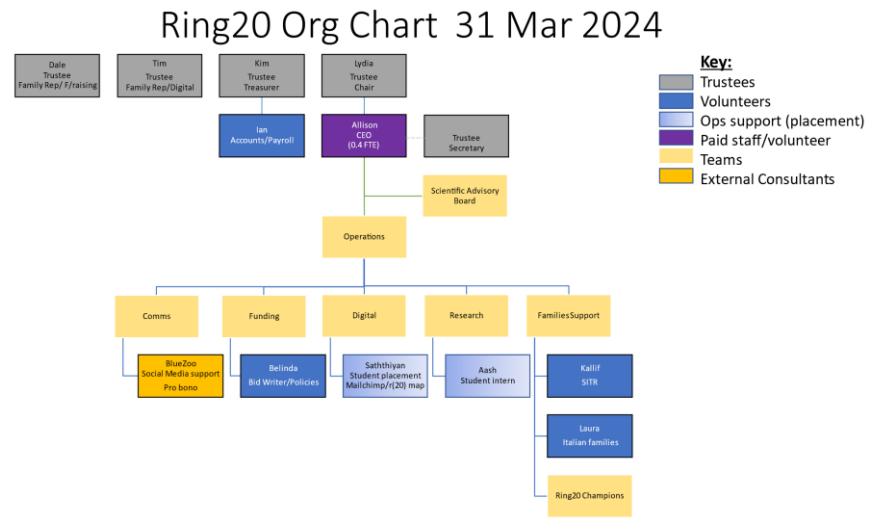
Additional governance issues (Optional information)

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.

- 1 part-time staff member (0.4 FTE)
- 4 part-time volunteers
- 6 student volunteers (various placements)

Activities are overseen by a Board of 5 Trustees supported by our International Scientific Advisory Board



Our CEO is responsible for operations management, volunteer management, communications, families support, fundraising support, research activities and also sits on the Board of Trustees as Secretary. Trustees operate in their specific areas of activity and consult on all significant matters of governance, including policies and strategic direction/oversight. New trustees are asked to abide by a Code of Conduct and are issued with [Essential Information for Trustees](#) from the Charities Commission, sign a Trustee Declaration and complete a Fit and Proper persons form. They also undergo a DBS check. Strategic planning is conducted at our annual AWAY DAY in March each year.

We expanded our Medical Advisory Board (MAB) to form a new International Scientific Advisory Board (SAB) comprising members from many countries and clinical disciplines meeting for the first time in October 2023. The SAB is chaired by Dr Antonio Gil-Nagel, Associate Head of Department of Neurology at Ruber International Hospital and director of the Epilepsy Program in Madrid, Spain. The SAB comprises 17 healthcare, researchers, scientists (details on our website [here](#).) We look forward to new opportunities arising from their vast clinical experience and contacts.

The charity has updated its insurance with an international underwriter to cover normal risks and operates the following policies: child protection, safeguarding, data privacy, risk management and volunteer, published on our website.

The charity is a member of:

- 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), Brentwood CVS, NCVO

Our CEO founded the UK Rare Epilepsies Together (UKRET) network

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

**What the charity does:**

- The Advancement Of Health Or Saving Of Lives
- Disability

Ring20 provide support and information to individuals, families and health professionals who are affected by, or come into contact with Ring Chromosome 20 Syndrome, or r(20) for short, an ultra-rare disease, the main symptom being difficult to treat epilepsy. We raise funds to help promote research into r(20) to try to improve overall quality of life for those living with the disease.

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

**1. Families Support/Information Services**

The charity provides a support group for individuals and families affected by the condition and a key aim is to connect families for mutual support and to reduce feelings of isolation. We aim to provide the latest information on r(20) to families and healthcare professionals via our website, eNewsletters and social media. Our website is auto-translated from English into 9 different languages to extend our reach to families affected across the world and the healthcare professionals that care for them.

Phone/email support is provided to families of those with the condition, as well as 1:1 video calls. We issue our regular eNews and provided continuous updates on social media every week.

We deliver regular online Coffee and Chat sessions via Zoom for our families to meet each other online and talk in a safe, supportive environment, as well as delivering our 'Step Into The Ring' virtual group sessions specifically for adults with r(20) to connect with their peers.

**2. Promoting opportunities for, and participating in, Research**

We attend various conferences, congresses and events throughout the year (online and in-person) to exhibit, speak and/or otherwise raise awareness of r(20) syndrome – the challenges and the opportunities relating to diagnosis, treatment and care. We use these events to network and build relationships with strategic partners from medics, to researchers and scientists, pharma and biotech, payers and regulators, with whom we may collaborate to engage in educational and research activities into better understanding of r(20).

The Trustees consider the charity's activities are wholly in the public interest and designed to benefit all those who suffer from r(20), their families and medical professionals dealing with this debilitating and life-limiting condition, in line with the Charity's Commission guidance on 'public benefit'.

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)

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 fortnightly helping to connect families in their own countries/languages.

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

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

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

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

- BlueZoo: helping to manage our social media activities
- Costello Medical – preparation for dashboard of patient impact survey results
- LawWorks/Gowlings: contractual support for research contracts
- LifeArc: draft T&Cs for research

### **Training**

Ring20 Trustees completed NSPCC's safeguarding training. Our Bid Writer volunteer completed various trainings in relation to her role. Trustee training has continued as needed related to specific areas of activity. Ring20 has benefitted from training webinars provided by EURORDIS and Beacon for Rare Diseases.

### **Mentoring**

Ring20 successfully recruited students mentored by our CEO.

Thank you to our placement students in the various tasks undertaken:

- London Metropolitan University – 30–150-hour placements
  - Diana Sescu (brand guidelines)
  - Izabela Wesolowska (graphic design templates)
  - Louise Harker (leaflet design/content)
  - Alex Tuckey (video editing)
  - Saththiyam Parameswaran (Mailchimp data clean-up)
- Aston University - 30 weeks, 1 day per week placement
  - Aashish Bishwakarma (supporting research)

Summary of the main achievements of the charity during the year

During the period notable achievements include:

### **FAMILIES SUPPORT**

In the reporting period we provided support and information services to >120 member families worldwide, >60% of the reported no. of cases of r(20) syndrome according to the latest medical literature. We welcomed 12 new families, demonstrating a 10% increase in our membership year on year. This is remarkable given as a charity, we have plotted a trend towards diagnostic decline in the last 5-10 years.

### **Ring20 Champions**

Our Champions continue to meet regularly online as a group. A newly formed informal support network has been established in Belgium, supporting families in Dutch and French.

Notably our Champions were instrumental in facilitating interviews in their native languages for the Patient Reported Impact Study and assisted with creation of new information leaflets for families and supporters of the charity.

### **RESEARCH**

#### **Research activities pursued in the period**

- A groundbreaking research Ring20 Patient Reported Impact Study co-created with Newcastle University was undertaken. This is the first survey of its kind in r(20) describing the lived experience of people living with Ring Chromosome 20 and their families. 85 respondents from 25 countries contributed to the study. The 75 questions in the study covered topics including demographics, diagnostic journey, seizures and comorbidities, treatments, medical and social support and the impact that living with this ultra rare disease has on everyday life. It was an opportunity for families to describe what it's really like to live with r(20) and had the additional benefit of forging new connections within the community. Publication of results is expected in 2025.
- Work towards the establishment of a Ring Chromosome Cohort within the NIHR BioResource continued.
- The charity's funds restricted for a proposed research study into the Natural History of r(20) syndrome remains unspent. The proposal we had been pursuing with Glasgow Children's Hospital for several years turned out not to be viable so the Trustees, on advice from our SAB, made a decision to tender for new proposals.
- The genomic research study in partnership with Illumina, involving patients supported by Ring20, to try to make diagnosis easier and find clues for better treatments which commenced in February 2023 continued throughout this reporting period. There were no clear findings and due to corporate restructuring at Illumina Inc, the research group undertaking this study was disbanded early in 2024 hence there was no write up of the research findings, which was disappointing.

Our CEO, together with Marco Crimi from Ring14, co-wrote a chapter in the [Human Ring Chromosomes A Practical Guide for Clinicians and Families](#) book published by Springer.

### **EDUCATING AND INFORMING**

#### **Conferences/Events attended including speaker opportunities:**

- Rare Disease Translational Challenge Launch Reception (Jul 23)
- RARESummit23, Cambridge (Oct 23)

## Section D

## Achievements and performance

- Research roundtable with Genomics England and (Oct 23)
- BPNA – drug resistant epilepsies meeting (Nov 23)
- Aspire Partnering event for Neurological/CNS disorders – pitch to pharma/biotech (Nov 23)
- BPNA UK Annual Conference (Jan 24)
- Rare Disease Day Parliamentary reception (Feb 24)
- Rare and Hot: climate change event (Mar 24)

### (Other) Awareness Raising Activities

- Participated in the M4RD/Beacon Student Voice Prize essay competition.

### LEADERSHIP

Our CEO leads the UK Rare Epilepsies Together network (UKRET) which she founded. It comprises UK based patient organisations representing all those living with rare and complex epilepsies, to improve diagnosis, treatment and care.

UKRET– approx. 2 days per month

- Organising/leading quarterly meetings
- Identifying and welcoming new charities to the network
- Seeking opportunities for collaborative activities
- Representing UKRET at conferences/events – speaker/exhibitor
  - Speaker: Birmingham Epilepsy Research Network (BERN)
  - Co-created a research roundtable with Genomics England
  - Beacon Rare Disease Showcase (Nov 23)
  - BPNA Annual Conference (Jan 24)
- Establishing UKRET as a small charity

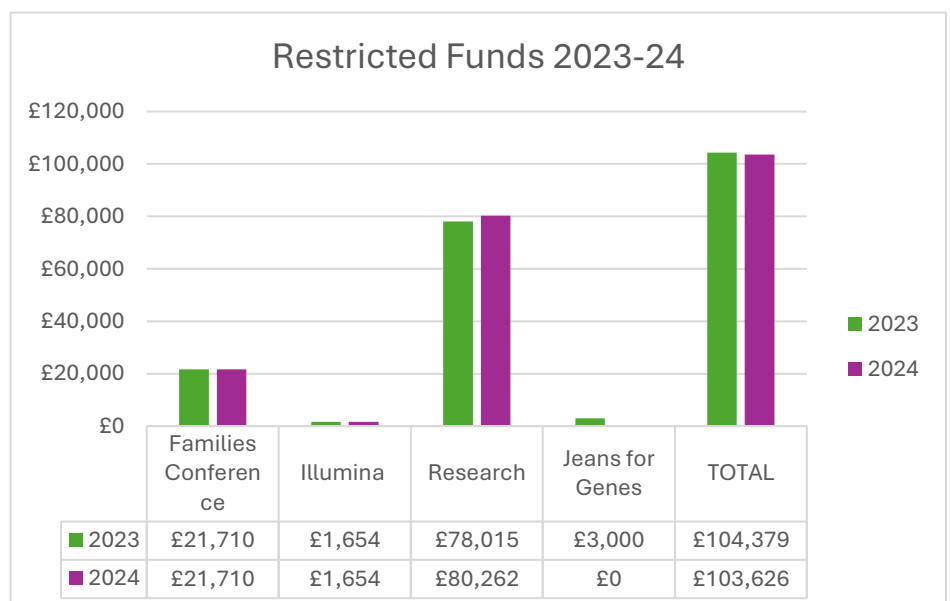
## Section E

## Financial review

Brief statement of the charity's policy on reserves

The charity receives funding for specific purposes which are restricted funds – these are dedicated to specific projects or items of expenditure.

Restricted Funds are retained as shown below, primarily towards a Families Conference and Natural History Research Study planned for 2025.



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 a general reserve in the range £10,000 - £12,000 to cover unfunded committed costs for the next 6 months.

<b>General Reserves before funds designated</b>	<b>£</b>	<b>44,954</b>
<b><u>Designated Funds</u></b>		
Salaries	£	17,245
Family Liaison Officer & CRM	£	9,234
Overheads (core costs)	£	3,000
<b>TOTAL FREE RESERVES</b>	<b>£</b>	<b>15,475</b>

Our general reserve as at 31 March 2024 was £44,954 (of which £29,479 has been designated as above) leaving £15,475 of Free Reserves, which is a little more than the reserves policy recommends.

Details of any funds materially in deficit

n/a

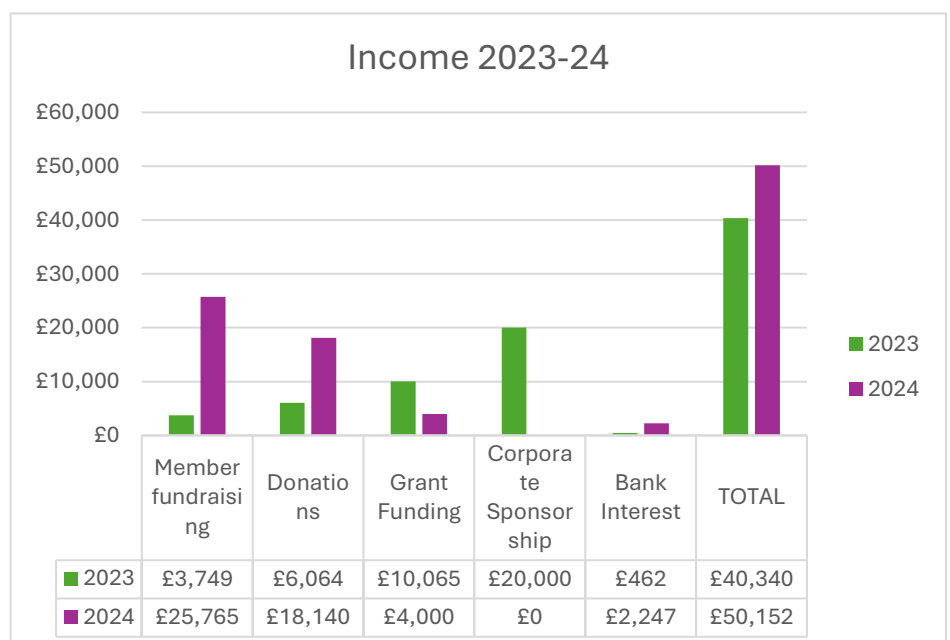
Further financial review details (Optional information)

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

During the period to 31 March 2024 the charity raised £50,152 through multiple income streams including Interest Received of £2,247.



Most funds were raised through donations and member fundraising, notably:

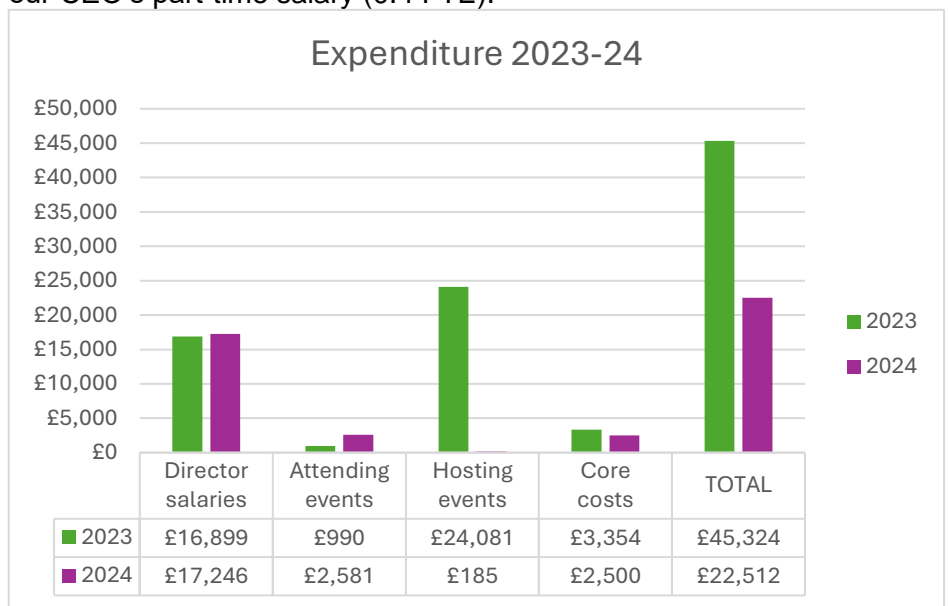
- £10,947 Ton's retirement donation (Netherlands)
- £1,623 Overseas member families' donations (USA/Germany)
- £1,000 Benevity donation (supporter nominated)
- £447 In Memory
- £27,317 In Memory: Sebastian Burckle, Marathon/Half marathon runners

We were grateful to receive grant funding of £4,000 from the Ninevah Trust towards the costs of our CEO's remuneration.

The charity intends to dedicate more consistent effort to securing grants in the next financial year with dedicated support from our volunteer bid writer (up to 2 days per week), to continue to diversify our income streams, to maintain sustainability of the charity.

**EXPENDITURE**

The charity spent £22,512 during the year, the majority of which was on our CEO's part-time salary (0.4 FTE).



Notably, salaries and core costs remain relatively unchanged year on year

**Section F Other optional information**

**Section G Declaration**

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

Signed on behalf of the charity's trustees

Signature(s) *Lydia Hirst* *Kim Parks*






Full name(s) Lydia Hirst Kim Parks

Position (eg Secretary, Chair, etc) Chair Treasurer

Date 19 / 10 / 2024

Title	Annual Trustee report 2024 DRAFT FINAL
File name	Annual Trustee re...4 DRAFT FINAL.pdf
Document ID	84ff2ac71976b0e62cc54e8caf7f5aef9bae0052
Audit trail date format	DD / MM / YYYY
Status	● Signed

### Document history

 SENT	<b>18 / 10 / 2024</b> 17:01:05 UTC	Sent for signature to Lydia Hirst (lydia@ring20researchsupport.co.uk) and Kim Parks (kim@parksbookkeeping.co.uk) from allison@ring20researchsupport.co.uk IP: 162.125.31.221
 VIEWED	<b>19 / 10 / 2024</b> 12:24:54 UTC	Viewed by Kim Parks (kim@parksbookkeeping.co.uk) IP: 2.126.243.119
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 COMPLETED	<b>24 / 10 / 2024</b> 08:36:14 UTC	The document has been completed.

# **RING20 RESEARCH AND SUPPORT UK CIO**

Charity number 1165651

## **FINANCIAL STATEMENTS FOR THE YEAR ENDED 31st MARCH 2024**



# RING20 RESEARCH AND SUPPORT UK CIO

## CONTENTS FOR THE YEAR ENDED 31 MARCH 2024

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---

# RING20 RESEARCH AND SUPPORT UK CIO

## RECEIPTS AND PAYMENTS ACCOUNT FOR THE YEAR ENDED 31 MARCH 2024

---

	Note	Unrestricted Fund £	Restricted Fund £	2024 Total £	2023 Total £
<b>Receipts:</b>					
Donations	2	18,140	-	18,140	6,064
Sponsorship/grant funding		-	4,000	4,000	30,065
Member fundraising		25,765	-	25,765	3,749
Interest received		-	2,247	2,247	462
<b>Total receipts</b>		<b>43,905</b>	<b>6,247</b>	<b>50,152</b>	<b>40,340</b>
<b>Payments:</b>					
<b>Charitable payments</b>					
Charitable activities	3	15,512	7,000	22,512	45,324
Fundraising expenditure		829	-	829	-
<b>Total payments</b>		<b>16,341</b>	<b>7,000</b>	<b>23,341</b>	<b>45,324</b>
<b>Net receipts/(payments)</b>		<b>27,564</b>	<b>(753)</b>	<b>26,811</b>	<b>(4,984)</b>
<b>Prior year adjustment</b>		-	-	-	627
<b>Transfer between funds</b>		-	-	-	-
<b>Net of receipts/(payments)</b>		<b>27,564</b>	<b>(753)</b>	<b>26,811</b>	<b>(4,357)</b>
<b>Cash funds brought forward</b>	5	17,587	104,379	121,966	126,323
<b>Cash funds carried forward</b>	5	<b>45,151</b>	<b>103,626</b>	<b>148,777</b>	<b>121,966</b>

The notes on page 3 - 4 form part of these accounts

# RING20 RESEARCH AND SUPPORT UK CIO

## STATEMENT OF ASSETS AND LIABILITIES AS AT 31 MARCH 2024

	Notes	2024 £	2023 £
<b><u>Cash funds</u></b>			
Current account		2,166	9,603
Deposit account		146,611	112,363
		<u>148,777</u>	<u>121,966</u>
<b><u>Represented by</u></b>			
Unrestricted funds	5	45,151	17,587
Restricted funds	5	103,626	104,379
		<u>148,777</u>	<u>121,966</u>
<b><u>Non-monetary assets/liabilities</u></b>			
<b><u>Current assets</u></b>			
Debtors		50	50
		<u>50</u>	<u>50</u>
<b><u>Liabilities</u></b>			
Independent examination fee		340	250
Creditors		249	-
		<u>589</u>	<u>250</u>
Total assets less liabilities		<u>(539)</u>	<u>(200)</u>

These accounts were approved by the Trustees, and signed on their behalf by:

Trustee:  \_\_\_\_\_

Date: 23rd September 2024

Name: Kim Parks

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

### 1. Accounting policies

#### Basis of the preparation of the accounts

These financial statements have been prepared under the historical cost convention and applicable accounting standards. The accounts are prepared on a cash basis.

#### Incoming resources

All material incoming resources have been included on a receivable basis i.e. they are included if the date receivable falls within the period covered by these accounts.

#### Resources expended

These have been analysed using a natural classification.

#### Going Concern

The charity is operating on a going concern basis.

1.1 These accounts are prepared on a receipts and payments basis.

### 2. Donations

	Unrestricted Fund £	Restricted Fund £	Total 2024 £	Total 2023 £
General donations	18,140	-	18,140	6,064
	<u>18,140</u>	<u>-</u>	<u>18,140</u>	<u>6,064</u>

### 3. Expenditure from charitable activities

	Unrestricted Fund £	Restricted Fund £	Total 2024 £	Total 2023 £
Cost of sales	-	-	-	-
Advertising/marketing	-	-	-	231
Attending conferences & events	2,187	394	2,581	990
Hosting conferences & events	-	185	185	24,081
Literature & materials	-	189	189	246
Website & emails	-	374	374	255
Accountancy, examination & audit	-	250	250	250
Director salaries	13,246	4,000	17,246	16,899
Office expenditure	22	331	353	112
Bank charges	-	95	95	169
Computer costs	-	219	219	292
Insurances	-	360	360	456
Postage	25	84	109	137
Subscriptions	32	245	277	236
Telephone	-	199	199	510
Training	-	75	75	460
	<u>15,512</u>	<u>7,000</u>	<u>22,512</u>	<u>45,324</u>

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

---

4. Funds analysis	Balance at 01/04/23 £	Incoming Funds £	Expended Funds £	Transfers in/out £	Balance at 31/03/24 £
<b>Unrestricted</b>					
Running costs	3,170	18,140	(15,512)	23,034	<b>28,832</b>
Fundraising	11,685	25,765	(829)	(36,621)	-
<b>Designated funds</b>					
Salaries	2,732	-	-	10,587	<b>13,319</b>
Overheads	-	-	-	3,000	<b>3,000</b>
	<u>17,587</u>	<u>43,905</u>	<u>(16,341)</u>	<u>-</u>	<u>45,151</u>
<b>Restricted funds</b>					
Family Conference	21,710	-	-	-	<b>21,710</b>
Illumina Research Project	1,654	-	-	-	<b>1,654</b>
Research Funds	78,015	2,247	-	-	<b>80,262</b>
Ninevah Trust	-	4,000	(4,000)	-	-
Jeans for Genes	3,000	-	(3,000)	-	-
<b>Total restricted funds</b>	<u>104,379</u>	<u>6,247</u>	<u>(7,000)</u>	<u>-</u>	<u>103,626</u>
<b>Totals</b>	<u>121,966</u>	<u>50,152</u>	<u>(23,341)</u>	<u>-</u>	<u>148,777</u>

### 5. Trustee payments

During 2024, one trustee received remunerations of £17,246 (2023: £15,999.96) as wages during the year.

### 6. Related party transactions

There were no related party transactions during the year.

### 7. Key management personnel

No staff have earned more than £60,000 during the year.

# RING20 RESEARCH AND SUPPORT UK CIO

## INDEPENDENT EXAMINER'S REPORT FOR THE YEAR ENDED 31 MARCH 2024

---

I report on the accounts of Ring20 Research and Support UK CIO for the year ended 31 March 2024 which are set out on pages 1 to 4.

### **Respective responsibilities of trustees and examiner**

The Charity's Trustees are responsible for the preparation of the accounts. The Charity's Trustees consider that an audit is not required for this year (under section 144 (2) of the Charities Act 2011 (The Act) but that an independent examination is needed.

It is my responsibility to:

- Examine the accounts under section 145 of the Charities Act,
- To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 145(5)(b) of the Charities Act, and
- To state whether particular matters have come to my attention.

### **Basis of independent examiner's Statement**

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the Charity and a comparison of the accounts presented with those records. It also includes considerations of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently I do not express an audit opinion on the view given by the accounts.

### **Independent examiner's statement**

In the course of my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of the accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair' view which is not a matter considered as part of an independent examination.

I have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

David Courtier FMAAT AATQB for and on behalf of:  
Community360  
Winsley's House, High Street, Colchester, Essex



Date 24/09/2024

# **RING20 RESEARCH AND SUPPORT UK CIO**

Charity number 1165651

## **FINANCIAL STATEMENTS FOR THE YEAR ENDED 31st MARCH 2024**



# RING20 RESEARCH AND SUPPORT UK CIO

## CONTENTS FOR THE YEAR ENDED 31 MARCH 2024

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# RING20 RESEARCH AND SUPPORT UK CIO

## RECEIPTS AND PAYMENTS ACCOUNT FOR THE YEAR ENDED 31 MARCH 2024

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These accounts were approved by the Trustees, and signed on their behalf by:

Trustee:  \_\_\_\_\_

Date: 23rd September 2024

Name: Kim Parks

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

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	<b>15,512</b>	<b>7,000</b>	<b>22,512</b>	<b>45,324</b>

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

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4. Funds analysis	Balance at 01/04/23 £	Incoming Funds £	Expended Funds £	Transfers in/out £	Balance at 31/03/24 £
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<b>Total restricted funds</b>	<u>104,379</u>	<u>6,247</u>	<u>(7,000)</u>	<u>-</u>	<u>103,626</u>
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### 5. Trustee payments

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### 6. Related party transactions

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### 7. Key management personnel

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# RING20 RESEARCH AND SUPPORT UK CIO

## INDEPENDENT EXAMINER'S REPORT FOR THE YEAR ENDED 31 MARCH 2024

---

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### **Respective responsibilities of trustees and examiner**

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David Courtier FMAAT AATQB for and on behalf of:  
Community360  
Winsley's House, High Street, Colchester, Essex



Date 24/09/2024

**RING20 RESEARCH AND SUPPORT UK CIO**

England & Wales - Charity number 1165651

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# Accounts

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# Trustees' Annual Report for the period

<b>From</b>	Period start date			<b>To</b>	Period end date		
	Day 01	Month April	Year 2022		Day 31	Month March	Year 2023

## 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

**Postcode**

**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	Allison Watson	CEO/Secretary		
3	Kim Parks	Treasurer		
4	Dale Ward	Patient Representative		
5	Tim Buckinx	Patient Representative	From Nov 2022	

### 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
Grant and Fundraising Consultant	Gemma Underwood	

### 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.

Other than our part-time CEO (16 hours per week) Ring20 is run on a voluntary basis. Our CEO volunteers an equal amount of her time to that which is paid.

In the reporting period the Ring20 team comprised 5 regular part-time volunteers, in addition to the CEO, taking on the roles of bid writing, accounts/payroll, families support, social media, research. Several of our family members also stepped up to act as Ring20 Champions, meeting fortnightly for 1 -1 ½ hours to discuss information and support for other families and helping to connect families in their own countries.

Trustees operate in their specific areas of activity but consult on all significant matters of policy formulation, family support and methods of communication about Ring20 information services to medical professionals. Trustee training has continued as needed related to specific areas of activity.

New trustees are asked to abide by a Code of Conduct and are issued with [Essential Information for Trustees](#) from the Charities Commission, sign a Trustee Declaration and complete a Fit and Proper persons form. They also undergo a DBS check. An org chart details our structure. One new board member was recruited in November 2022, as a patient representative Trustee.

The Medical Advisory Board remains in place with Dr Ailsa McLellan leading as acting Ring20 Chief Medical Advisor, taking over from Prof Sameer Zuberi who stepped down in Feb 23.

The charity has updated its insurance with an international underwriter to cover normal risks and operates the following policies: child protection, data privacy, risk management and volunteer management, published on our website.

#### The charity is a member of:

- Brentwood CVS
- Genetic Alliance UK (GAUK)
- Neurological Alliance
  - CEO represents Ring20 in the Rare Disease sub-group
- EURORDIS
- Rare Revolution Magazine
- International Bureau for Epilepsy (IBE)
- Rare Epilepsy Network (REN)
- UK Rare Epilepsies Together network (UKRET)

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

To support families, individuals and medical professionals who are affected by, or come into contact with, Ring Chromosome 20 Syndrome.

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.

**Families Support/Information Services**

The charity provides a support group for individuals and families affected by the condition. We aim to provide the latest information on the condition to families and health professionals via our website, enews and social media.

**Educational Activities**

We continue to work on raising both public awareness and education amongst key medical professionals throughout the world so they can relate to the signs, symptoms and medical diagnosis of r(20) syndrome. Speaking at and/or hosting an exhibition stand (in-person or virtually) at medical and scientific conferences provides opportunities to fulfil our aims and objectives whilst developing strategic partnerships with research facilities, medical and pharmaceutical institutions, and like-minded charitable bodies.

**Research**

The charity has raised funds to pay for proposed research to be undertaken by Glasgow University Hospital into the Natural History and biomarkers of r(20) syndrome including the creation of a patient registry for those currently diagnosed with the disease. Commencement of the study continues to be further delayed post the COVID-19 pandemic despite a financial offer letter sent July 2022.

A research study in partnership with Illumina, involving patients supported by Ring20, to improve the diagnostic journey commenced in February 2023 – results are expected in 2024.

A new piece of research with Newcastle University is under discussion with the intention of carrying out the research in 2023. This will involve interviews with the families in our community to understand more about the impact of living with Ring20. Interviews will be undertaken by volunteers and the research project will be led by the University. Analysis and a paper will follow.

The Trustees consider the charity's activities are wholly in the public interest and designed to benefit all those who suffer from r(20), their families and medical professionals dealing with this debilitating condition, in line with the Charity's Commission guidance on 'public benefit'.

**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)**

**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 all their volunteers for their support throughout the year.

Special mention should go to our volunteers during the period:

- Belinda Hunt (Bid Writing)
- Kallif Garlicki (Families Support)
- Laura Giordana (Comms and Italian support)
- Ian Allen (Accounts/Payroll)
- Clara Tang (Research)
- Our Ring20 Champions:
  - Yvonne Goodson (UK)
  - Carl Darby (UK)
  - Andre Reis e Silva (Portugal)
  - Steve Baumley (USA)

- Junko Okuda (USA/Japan)

We would also like to thank those who provided pro bono support during the year:

- BlueZoo: helping to manage our social media activities.
- LawWorks/Gowlings: contractual support for research contracts
- LifeArc: draft T&Cs for research

**Summary of the main achievements of the charity during the year**

**During the period a number of aims were achieved:**

**Funding/Fundraising**

The new bid writer has been much more systematic in her approach to applications for grant funding. Unfortunately, part of the post Covid world, has meant a reduction in potential funds and the success rate has been low.

Notable member fundraising events included a 24-hour Gamethon, Family Fun Day, sponsored hike, marathon runners, plus several birthday fundraisers on Facebook by members from across the globe.

**RESEARCH**

UNRAVEL Phase II: Making genomic understanding of r(20) possible

Following blood sample collection from selected families facilitated by the NIHR Bioresource, Illumina commenced an R&D genomic sequencing study on DNA samples.

Ring Chromosome Rare Disease Research Cohort

We were proud to have applied for and been approved for a rare new disease research cohort for Ring Chromosome disorders by the NIHR Bioresource. We plan to start patient recruitment in 2024 supported by Unique – rare chromosome disorder patient group.

New research project with Newcastle University due to start in 2023 (as above).

The Trustee Board would like to create a broader Scientific Advisory Board to take over from the existing Medical Advisory Board. The CEO with help from Trustee, Tim Buckinx, will contact individuals known to have an interest in the rare Ring20 condition. These will be drawn from researchers in different countries, geneticists, epilepsy nurses, neurologists and more. The charity recognises the need to be proactive in identifying research projects to further knowledge into the condition as well as seeking funding for research.

A decision was taken that the charity cannot currently afford to invest £10K p.a. in a formal registry. For now, this will be created without the software on a smaller scale.

**FAMILIES SUPPORT**

Information and Service Provision

Phone/email support was provided to families of those with the condition, as well as 1:1 video calls. We issued our enews bi-monthly and provided continuous updates on social media every week.

We continued our regular online Coffee and Chat sessions via Zoom for our families to meetup online and talk in a safe, supportive environment as well as our 'Step Into The Ring' virtual group specifically for adults with r(20) to connect with their peers.

Families Conference (including Wellbeing Workshops)

A key highlight of the year was our 2<sup>nd</sup> ever Families Conference weekend event in Cambridge, kindly hosted and sponsored by Illumina Inc. The event was mostly delivered hybrid. So that families and interested medical professionals/others could choose to join either in-person or online. The event was attended in-person by 17 r(20) families from countries including UK, Belgium, Netherlands, Slovenia, USA and Australia.

Incorporating our AGM, we kicked off on the Friday evening with a review of Ring20 the charity – our services, team and plans for the future. Our Ring20 Champions were key contributors to this, and we also had a guest speaker from Ring14 Italy to share the Ring14 International model of patient support. We took the opportunity to ask our families feedback on our ring20 services – what's working well and what they want more of. On the Saturday we were privileged to deliver a day of speakers (including healthcare professionals, geneticists, scientists, researchers, pharma representatives, patient family representatives) covering topics such as genomics, research and clinical care and treatments as well as patient family real-world experiences. An educational treat for our families was a private tour of the Illumina sequencing labs on the Wellcome genome campus and strawberry DNA extraction by the Illumina training team which were widely enjoyed.



On the Sunday, as a result of funding secured from London Catalyst/Partners for Health, we were able to run 3 concurrent Wellbeing workshops to improve mental health and relieve feelings of isolation for our mums, dads and young people diagnosed with r(20) syndrome.

#### **Conferences/Events attended + speaker opportunities:**

- Epilepsy Research UK Shape Network, London (May 22) – latest in epilepsy research
- CRDN Companies Forum - pharma/biotech discussion on Priority 2 of Rare Disease Framework – educating clinicians in rare diseases (June 22)
- ECRD – (speaker) Inequalities in accessing education, work, independent living (June 22)
- Congenica Patient Engagement Advisory Board – the Ring20 org journey (July 22)
- Patient Engagement Day webinar (Sep '22)
- Gene People Leadership Symposium (Nov 22)
- RAREfest22, Cambridge (Nov 22)
- Aspire Partnering event for Neurological/CNS disorders – pitch to pharma/biotech (Nov 22)
- Festival of Genomics, London (Jan 23)
- BPNA UK Annual Conference – UKRET shared exhibition stand (Jan 23)

- M4RD: The unusual suspects: Rare disease in everyday medicine (Feb 23)
- Rare Disease Day Parliamentary reception (Feb 23)
- Rare epilepsies awareness event at Young Epilepsy (UKRET)– in-person (Mar 22)

#### **(Other) Awareness Raising Activities**

- Participated in the M4RD/Beacon Student Voice Prize essay competition.
- Medics4RareDisease: social media posts for young healthcare professionals, part of their “Mystery Mondays” educational series
- Our work with NIHR BioResource was used by Dept of Health and Social Care as a case study for Rare Disease Day (Feb 23)

#### **CEO networking included:**

At the end of December 2022 our CEO stepped down from her role in EpiCARE the European Reference Network (ERN) for rare and complex epilepsies sitting on the steering committee and co-leading the European Patient Advocacy Group (ePAG) for the ERN after >5 years in post. This is to focus more on Ring20 and the development of the UKRET network.

- ePAG EpiCARE – ePAG co-lead (until 31<sup>st</sup> Dec '22) – average 1+ days per week (ePAG co-lead, member of Executive Committee, ePAG rep on Research Council)
  - Provided feedback on the new eLearning module for clinicians on r(20) syndrome
  - EURORDIS volunteer – 210 hrs (26 ¼ days) in 22

Our CEO leads the UK Rare Epilepsies Network (UKRET) she founded comprising patient organisations across the UK representing individuals and families living with rare and complex epilepsies.

- UKRET– average 2 days per month
  - Organising/leading quarterly meetings
  - Working with Epilepsy Action and ATOS/DWP on new assessment criteria for PIP for rare epilepsies
  - Working with Young Epilepsy on organising a rare epilepsies event Sept 2022
  - Identifying and welcoming new charities to the network
  - Seeking opportunities for collaborative activities

- CamRARE Companies Forum (2-3 x per year)
- RC Net – monthly meeting. Support with bid writing
- Genetic Alliance PEG and PAG (input to UK Rare Diseases Framework/action plan)
- BPNA Charities Forum
- Neurological Alliance: rare diseases sub-group rep
- GO FAIR – patient registry group

#### **CEO supporting other charities**

- Supporting PLRH/CamRARE in grant application for Rare Disease Research Network
- BPNA PET1 Training for paediatric neurologist – patient representative input/feedback on training course (Feb 23)
- Input to the Epilepsy Research UK Priority Setting Partnership (PSP) to identify the Top10 priorities for UK epilepsy research.

#### **Training/mentoring:**

Ring20 benefits from services provided by EURORDIS, Beacon for rare diseases, CamRARE-including mentoring, training, and networking opportunities.

- Workshop | Demonstrating impact: the key to success (July 22)

## Section D

## Achievements and performance

- Workshop | Building positive partnerships between patient groups (Sep 22)
- Navigating the CoL crisis: Building resilience to better face challenges (Mar 23)
- NCVO: Outcomes and impact measurement

Ring20 successfully recruited 3 students who our CEO mentored to develop 3 family case studies and conducted some impact assessment of our current activities (Mar 22)

A further 8 students were recruited from London Metropolitan University (Mar 23) to commence work on 2 projects:

- Developing promotional materials and brand guidelines for Ring20
- Building a website for the URET network

## Section E

## Financial review

### Brief statement of the charity's policy on reserves

The charity receives funding for specific purposes which are restricted funds – these are not available for expenditure on other purposes. 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 a general reserve in the range £10,000 - £12,000 to cover unfunded committed costs for the next 6 months.

Our general reserve as at 31 March 2023 was £17,637.64 (of which £13,246 has been designated for salaries and £3,000 designated for running costs), leaving £1,391.64 of Free Reserves which is slightly in excess of policy. The Board will review the policy in Q4 2023.

### Details of any funds materially in deficit

n/a

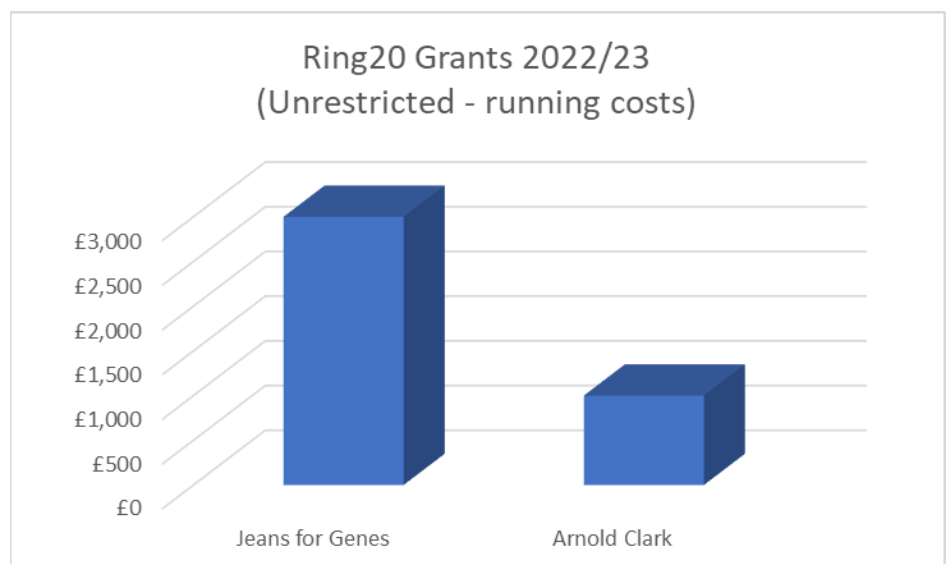
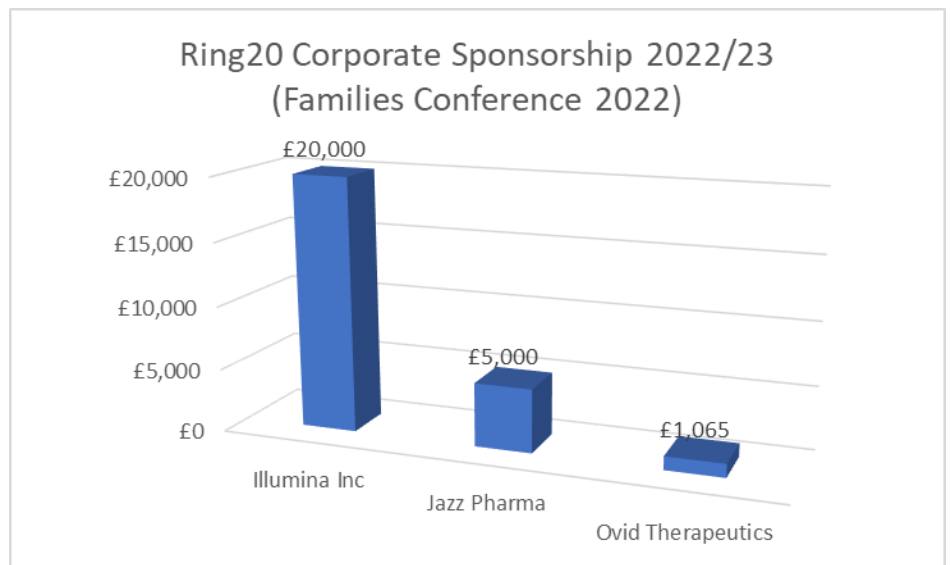
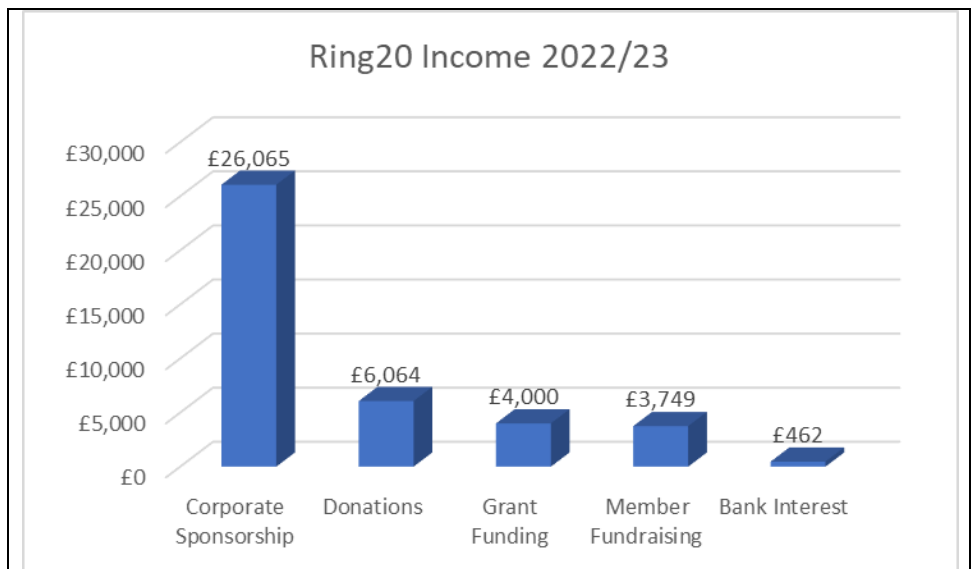
### Further financial review details (Optional information)

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

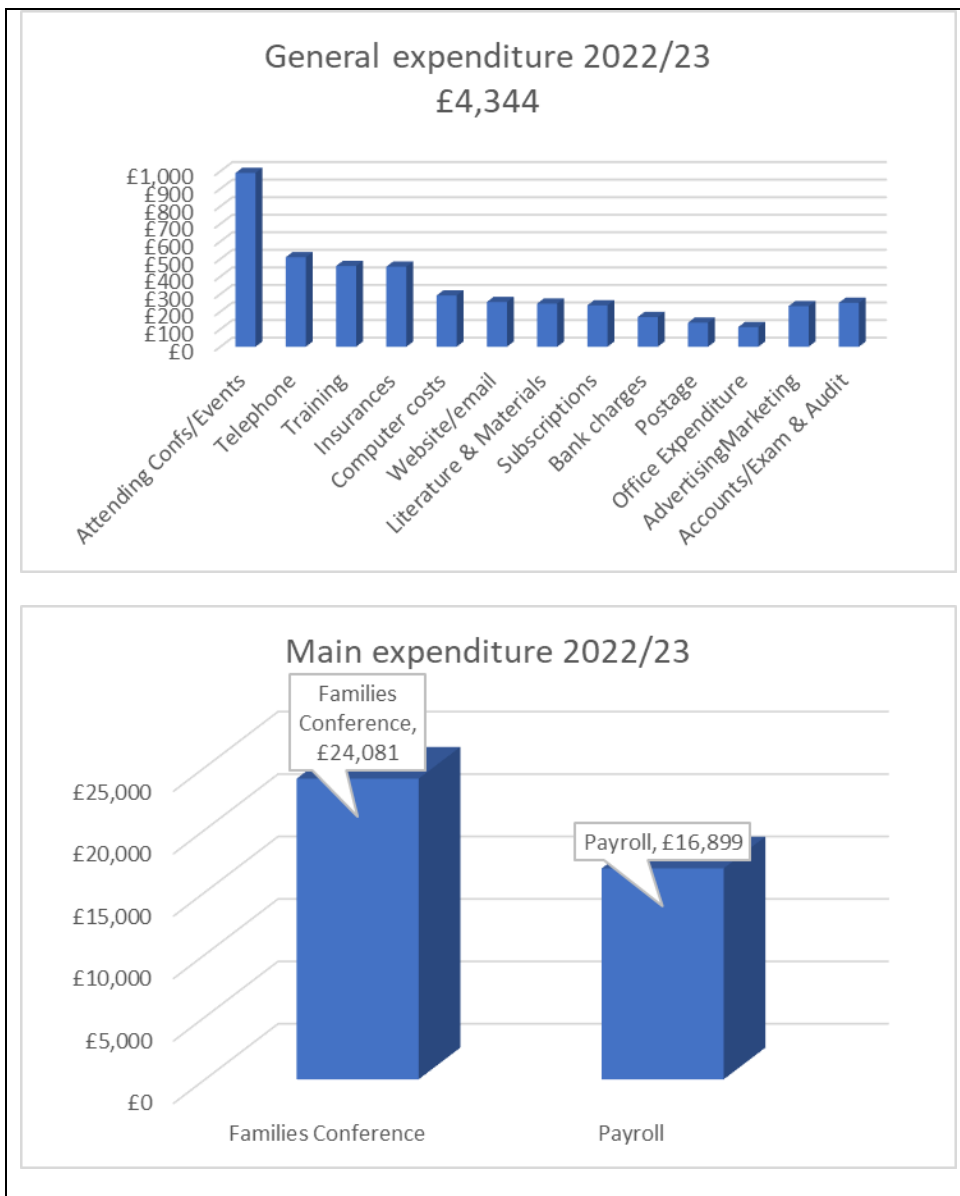
- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;

During the period to 31 March 2023 the charity raised £40,340 through multiple income streams including Interest Received of £462.

- investment policy and objectives including any ethical investment policy adopted.



The charity spent £45,324 of which the main items of expenditure in support of its objectives are shown below:

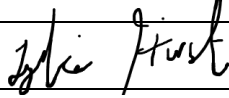
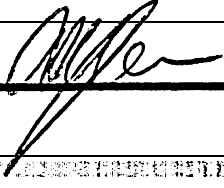


**Section F Other optional information**

**Section G Declaration**

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

Signed on behalf of the charity's trustees

<b>Signature(s)</b>		
<b>Full name(s)</b>	Lydia Hirst	Allison Watson
<b>Position (eg Secretary, Chair, etc)</b>	Chair	Secretary
<b>Date</b>	03 / 12 / 2023	

<b>Title</b>	Annual Trustee report 2023 FINAL (signed)
<b>File name</b>	Annual Trustee re...INAL (signed).pdf
<b>Document ID</b>	af5f14bd163cc412282c7694cb2b067fac30e8d8
<b>Audit trail date format</b>	DD / MM / YYYY
<b>Status</b>	● Signed

### Document history



SENT

**29 / 11 / 2023**

20:32:48 UTC

Sent for signature to Lydia Hirst  
(lydia@ring20researchsupport.co.uk) from  
allison@ring20researchsupport.co.uk  
IP: 162.125.31.121



VIEWED

**03 / 12 / 2023**

15:06:38 UTC

Viewed by Lydia Hirst (lydia@ring20researchsupport.co.uk)  
IP: 82.39.102.177



SIGNED

**03 / 12 / 2023**

15:07:21 UTC

Signed by Lydia Hirst (lydia@ring20researchsupport.co.uk)  
IP: 82.39.102.177



COMPLETED

**03 / 12 / 2023**

15:07:21 UTC

The document has been completed.

# **RING20 RESEARCH AND SUPPORT UK CIO**

Charity number 1165651

## **FINANCIAL STATEMENTS FOR THE YEAR ENDED 31st MARCH 2023**



# RING20 RESEARCH AND SUPPORT UK CIO

## CONTENTS FOR THE YEAR ENDED 31 MARCH 2023

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	Page
Receipts and payments account	1
Statement of assets and liabilities	2
Notes to the accounts	3-4
Independent examiner's report	5

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# RING20 RESEARCH AND SUPPORT UK CIO

## RECEIPTS AND PAYMENTS ACCOUNT FOR THE YEAR ENDED 31 MARCH 2023

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	Note	Unrestricted Fund £	Restricted Fund £	2023 Total £	2022 Total £
<b>Receipts:</b>					
Donations	2	5,749	315	6,064	3,708
Sponsorship/grant funding		1,000	29,065	30,065	23,800
Member fundraising		3,749	-	3,749	12,958
Interest received		-	462	462	10
<b>Total receipts</b>		<b>10,498</b>	<b>29,842</b>	<b>40,340</b>	<b>40,476</b>
<b>Payments:</b>					
<b>Charitable payments</b>					
Charitable activities	3	8,945	36,379	45,324	32,453
<b>Total payments</b>		<b>8,945</b>	<b>36,379</b>	<b>45,324</b>	<b>32,453</b>
<b>Net receipts/(payments)</b>		<b>1,553</b>	<b>(6,537)</b>	<b>(4,984)</b>	<b>8,022</b>
<b>Prior year adjustment</b>		627	-	627	-
<b>Transfer between funds</b>		-	-	-	-
<b>Net of receipts/(payments)</b>		<b>2,180</b>	<b>(6,537)</b>	<b>(4,357)</b>	<b>8,022</b>
<b>Cash funds brought forward</b>	5	15,407	110,916	126,323	118,300
<b>Cash funds carried forward</b>	5	<b>17,587</b>	<b>104,379</b>	<b>121,966</b>	<b>126,323</b>

The notes on page 3 - 4 form part of these accounts

# RING20 RESEARCH AND SUPPORT UK CIO

## STATEMENT OF ASSETS AND LIABILITIES AS AT 31 MARCH 2023

	Notes	2023 £	2022 £
<b><u>Cash funds</u></b>			
Current account		9,603	4,748
Deposit account		112,364	121,574
		<b>121,966</b>	<b>126,323</b>
<b><u>Represented by</u></b>			
Unrestricted funds	5	17,587	15,407
Restricted funds	5	104,379	110,916
		<b>121,966</b>	<b>126,323</b>
<b><u>Non-monetary assets/liabilities</u></b>			
		<b>2023 £</b>	<b>2022 £</b>
<b><u>Current assets</u></b>			
Debtors		50	752
		50	752
<b><u>Liabilities</u></b>			
Independent examination fee		250	250
Other creditors		-	378
		250	628
Total assets less liabilities		<b>(200)</b>	<b>124</b>

These accounts were approved by the Trustees, and signed on their behalf by:

Trustee:  \_\_\_\_\_

Date: 4th December 2023

Name: Kim Parks, Treasurer & Trustee

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023

### 1. Accounting policies

#### Basis of the preparation of the accounts

These financial statements have been prepared under the historical cost convention and applicable accounting standards. The accounts are prepared on a cash basis.

#### Incoming resources

All material incoming resources have been included on a receivable basis i.e. they are included if the date receivable falls within the period covered by these accounts.

#### Resources expended

These have been analysed using a natural classification.

#### Going Concern

The charity is operating on a going concern basis.

1.1 These accounts are prepared on a receipts and payments basis.

### 2. Donations

	Unrestricted Fund £	Restricted Fund £	Total 2023 £	Total 2022 £
General donations	5,749	315	6,064	3,708
	<u>5,749</u>	<u>315</u>	<u>6,064</u>	<u>3,708</u>

### 3. Expenditure from charitable activities

	Unrestricted Fund £	Restricted Fund £	Total 2023 £	Total 2022 £
Cost of sales	-	-	-	180
Advertising/marketing	31	200	231	-
Attending conferences & events	723	267	990	316
Hosting conferences & events	104	23,977	24,081	1,561
Literature & materials	43	203	246	4,805
Website & emails	255	-	255	3,178
Accountancy, examination & audit	250	-	250	250
Wages	-	-	-	2,274
Director salaries	5,344	11,555	16,899	16,392
Office expenditure	3	109	112	27
Bank charges	169	-	169	154
Computer costs	269	23	292	1,362
Insurances	456	-	456	453
Postage	92	45	137	66
Subscriptions	236	-	236	188
Telephone	510	-	510	389
Training	460	-	460	858
	<u>8,945</u>	<u>36,379</u>	<u>45,324</u>	<u>32,453</u>

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023

4. Funds analysis	Balance at 01/04/22 £	Incoming Funds £	Expended Funds £	Transfers in/out £	Balance at 31/03/23 £
<b>Unrestricted</b>					
Running costs	1,412	4,931	(3,173)	-	3,170
Fundraising	5,522	6,194	(31)	-	11,685
<b>Designated funds</b>					
Salaries	8,473	-	(5,741)	-	2,732
	<u>15,407</u>	<u>11,125</u>	<u>(8,945)</u>	<u>-</u>	<u>17,587</u>
<b>Restricted funds</b>					
Family Conference	25,430	26,380	(30,100)	-	21,710
Illumina Research Project	1,921	-	(267)	-	1,654
Research Funds	77,553	462	-	-	78,015
Mental Health Workshops	6,013	-	(6,013)	-	-
Jeans for Genes	-	3,000	-	-	3,000
<b>Total restricted funds</b>	<u>110,917</u>	<u>29,842</u>	<u>(36,380)</u>	<u>-</u>	<u>104,379</u>
<b>Totals</b>	<u><u>126,323</u></u>	<u><u>40,967</u></u>	<u><u>(45,325)</u></u>	<u><u>-</u></u>	<u><u>121,966</u></u>

### 5. Trustee payments

During 2023, one trustee received remunerations of £15,999.96 (2022: £15,999.96) as wages during the year.

### 6. Related party transactions

There were no related party transactions during the year.

### 7. Key management personnel

No staff have earned more than £60,000 during the year.

# RING20 RESEARCH AND SUPPORT UK CIO

## INDEPENDENT EXAMINER'S REPORT FOR THE YEAR ENDED 31 MARCH 2023

---

I report on the accounts of Ring20 Research and Support UK CIO for the year ended 31 March 2023 which are set out on pages 1 to 4.

### **Respective responsibilities of trustees and examiner**

The Charity's Trustees are responsible for the preparation of the accounts. The Charity's Trustees consider that an audit is not required for this year (under section 144 (2) of the Charities Act 2011 (The Act) but that an independent examination is needed.

It is my responsibility to:

- Examine the accounts under section 145 of the Charities Act,
- To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 145(5)(b) of the Charities Act, and
- To state whether particular matters have come to my attention.

### **Basis of independent examiner's Statement**

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the Charity and a comparison of the accounts presented with those records. It also includes considerations of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently I do not express an audit opinion on the view given by the accounts.

### **Independent examiner's statement**

In the course of my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of the accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair' view which is not a matter considered as part of an independent examination.

I have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

David Courtier FMAAT AATQB for and on behalf of:

Community360   
Winsley's House, High Street, Colchester, Essex

Date 8/12/2023

# RING20 RESEARCH AND SUPPORT UK CIO

## INDEPENDENT EXAMINER'S REPORT FOR THE YEAR ENDED 31 MARCH 2023

---

I report on the accounts of Ring20 Research and Support UK CIO for the year ended 31 March 2023 which are set out on pages 1 to 4.

### **Respective responsibilities of trustees and examiner**

The Charity's Trustees are responsible for the preparation of the accounts. The Charity's Trustees consider that an audit is not required for this year (under section 144 (2) of the Charities Act 2011 (The Act) but that an independent examination is needed.

It is my responsibility to:

- Examine the accounts under section 145 of the Charities Act,
- To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 145(5)(b) of the Charities Act, and
- To state whether particular matters have come to my attention.

### **Basis of independent examiner's Statement**

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the Charity and a comparison of the accounts presented with those records. It also includes considerations of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently I do not express an audit opinion on the view given by the accounts.

### **Independent examiner's statement**

In the course of my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of the accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair' view which is not a matter considered as part of an independent examination.

I have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

David Courtier FMAAT AATQB for and on behalf of:

Community360   
Winsley's House, High Street, Colchester, Essex

Date 8/12/2023

**RING20 RESEARCH AND SUPPORT UK CIO**

England & Wales - Charity number 1165651

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# Accounts

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# Trustees' Annual Report for the period

<b>From</b>	Period start date			<b>To</b>	Period end date		
	Day 01	Month April	Year 2021		Day 31	Month March	Year 2022

## 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**

26 Headley Chase

Brentwood

Essex

**Postcode**

CM14 5BN

### 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	Allison Watson	CEO/Secretary		
3	Kim Parks	Treasurer		
4	Chris Sullivan	Fundraiser		
5	Dale Ward	Patient Representative	From Dec 21	
6	Claire Sullivan	Fundraiser	To Nov 21	
7	Neil White	Chairperson (resigned)	To Oct 21	

### 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
Grant and Fundraising Consultant	Gemma Underwood	

### 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.

Trustees operate in their specific areas of activity but consult on all significant matters of policy formulation, family support and methods of communication about Ring20 information services to medical professionals. Trustee training has continued as needed related to specific areas of activity. One new board member was recruited in December 2021, as a patient representative Trustee. The previous Chair stepped down in Oct 2021, as did one of our Fundraising Trustees.

The Medical Advisory Board remains in place with Prof Sameer Zuberi leading as Ring20 Chief Medical Advisor.

The charity is a member of:

- Brentwood CVS
- Genetic Alliance UK
- Neurological Alliance
  - CEO represents us in the Rare Disease sub-group
- EURORDIS
  - CEO is a EURORDIS volunteer
- Rare Revolution Magazine
- International Bureau for Epilepsy (IBE)
- Rare Epilepsy Network (REN)
- Commission for Neurodevelopmental CNVs

and benefits from services provided by EURORDIS, Findacure (now Beacon), CRDN-including mentoring, training and networking opportunities.

Our CEO participates in the British Paediatric Neurology Association (BPNA) charities forum and leads the UK Rare Epilepsies Network she founded (UK RET) comprising patient organisations across the UK representing individuals and families living with rare and complex epilepsies.

Our CEO continues to provide a significant contribution to EpiCARE the European Reference Network (ERN) for rare and complex epilepsies sitting on the steering committee and co-leads the European Patient Advocacy Group (ePAG) for the ERN. Allison's role continues to develop and broaden constantly bringing the patient family perspective into discussions.

Further our CEO has input to the new UK Rare Disease Framework Action Plan for England.

The charity has updated its insurance with an international underwriter to cover normal risks and operates the following policies: child protection, data privacy, risk management and volunteer, published on our website.

## Section C Objectives and activities

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

To support families, individuals and medical professionals who are affected by, or come into contact with, Ring Chromosome 20 Syndrome.

### 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.

The charity provides a support group for individuals and families affected by the condition. We aim to provide the latest information on the condition to families and professionals via our website, regular enews and social media.

We continue to work on raising both public awareness and education amongst key medical professionals throughout the UK and Europe so they can relate to the signs, symptoms and medical diagnosis of r(20) syndrome. Speaking at and/or hosting an exhibition stand (in-person or virtually) at medical and scientific conferences provides opportunities to fulfil our aims and objectives whilst developing strategic partnerships with research facilities, medical institutions and like-minded charitable bodies.

The charity has raised funds to pay for research to be undertaken by Glasgow University Hospital into a Natural History study and registry for those currently diagnosed with the disease, commencement of the study has been further delayed due to the COVID-19 pandemic. Another research study is proposed in 2022/23 in partnership with Illumina, involving patients supported by Ring20, to improve the diagnostic journey.

The Trustees consider the charity's activities are wholly in the public interest and designed to benefit all those who suffer from r(20), their families and medical professionals dealing with this debilitating condition, in line with the Charity's Commission guidance on 'public benefit'.

### 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 all their volunteers for their support throughout the year.

Special mention should go to our newest volunteers recruited during the period:

- Kallif Garlicki (Families Support)
- Laura Giordana (Comms)
- Ian Allen (Accounts)
- Clara Tang (Research)
- Shahid Mughal (Operations Management) to Jun 21
- Ana Vieitez (Funding) to Dec 21
- Jon Dunn (Ring20 map)

We also employed the services of the following part-time staff member for 5 months:

- Vinay Pitrola (Digital Marketing Apprentice) to Sep 21

### Summary of the main achievements of the charity during the year

#### During the period a number of aims were achieved:

Due to the pandemic fundraising events remained significantly reduced this year. However, we benefitted unexpectedly from 'In Memory' fundraising following the passing of one of our members. continued to reach out digitally to our members, supporters, and wider audience by introducing and/or attending virtual events.

#### Upgraded website

We launched our newly upgraded website which remains a key source for all topical information on r(20) syndrome and the charity's activities – we now have auto translation in 6 languages.

#### UNRAVEL Phase I: Making genomic understanding of r(20) possible

We launched a new educational project comprising a variety of assets on our website explaining the basics of the genetics of r(20) syndrome for the benefit of families and healthcare professionals. The highlight was the production of a short animation film.

#### Families Support

Phone/email support was provided to families of those with the condition, as well as some 1:1 video calls. We issued our enews monthly and provided continuous updates on social media every week. We continued our regular online Coffee and Chat sessions via Zoom for our families to meetup online and talk in a safe, supportive environment. We also initiated a new virtual meeting group 'Step Into The Ring' specifically for adults with r(20) to connect with their peers.

#### Wellbeing Workshops

As a result of funding secured from Pears Foundation, we began a short series of Wellbeing workshops to improve mental health and relieve feelings of isolation for our parents/carers.

#### Conferences/Events attended:

- Epilepsy Foundation Research Roundtable for epilepsy – speaker (Apr 21)
- CRDN Companies Forum (May 21)
- EJPRD General Assembly - speaker (Sep 21)
- CRDN RareSummit – speaker (Oct 21)
- Global Keto – exhibition stand (Oct 21)
- In Search of Lost Time, Rome virtual workshop (Dec 21)
- BPNA UK Annual Conference – virtual exhibition stand and Paediatric Neurology Charities Meeting (Jan 22)
- Beacon Int'l Rare Disease Showcase – virtual exhibit (Feb 22)

#### Training/mentoring:

Apprenticeship Training – Aspire2Learn  
 Ensuring inclusive communications around genetics (Apr 21)  
 Patient group experiences of using data (May 21)  
 Raising the profile of your condition (Oct 21)  
 Creating a presence: increasing visibility of your patient group (Mar 22)  
 Sustaining engagement from your patient community (Mar 22)

**Brief statement of the charity's policy on reserves**

The charity receives funding for specific purposes which are restricted funds – these are not available for expenditure on other purposes. 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 a general reserve in the range £10,000 - £12,000 to cover unfunded committed costs for the next 6 months.

Our general reserve as at 31 March 2022 was £15,780 (of which £8,400 has been designated for salaries), leaving £7,380 of Free Reserves which is slightly in excess of policy. The Board will review the policy in Q4 2022.

**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.

During the period to 31 March 2021 the charity raised £39,515 through multiple income streams including Interest Received of £10 (0.001%):

**Donations £3,758 (9.5%)****Corporate £1,500 (3.8%)**

- Bank of Ireland £450
- Movement for Good £1,000
- Other £50

**Members £626 (1.7%)**

- Ad hoc (various) £304
- Regular Donations £322

**Online £583 (1.5%)**

- easyfundraising, SmileAmazon, Essex Lottery. PayPal Giving

**Facebook Fundraisers £963 (2.4%)**

- of which from Overseas £784

**Raffles, online games of chance £86 (0.2%)****Grant Funding £22,800 (57.7%)**

- Brian Mercer Trust Restricted £12,500
- Pears Foundation Restricted £5,000
- HSF/London Catalyst Restricted £5,000
- Marsh Christian Trust £300

**Member Fundraising £12,958 (32.8%)**

- Shahid Triathlon **Restricted** £615
- Kirstie Hansford 'In Memory' **Restricted** £9,432
- Bonus Ball lottery x2 (N Middleton) £486
- Body shop raffle (J Haggerty) £122

➤ JustGiving (various)	£1,695
➤ Georgia Duffy: Great North Run	£472
➤ Collection pots	£136
<b>HMRC gift aid including GASDS £0 (0%)</b>	
The charity spent £30,400 of which the main items of expenditure in support of its objectives were:	
➤ Staff salaries	£17,739
➤ Website	£3,178
➤ UNRAVEL Animation	£4,534
➤ Wellbeing workshops	£1,272
➤ Computer costs	£1,362

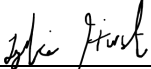

**Section F Other optional information**

--

**Section G Declaration**

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

Signed on behalf of the charity's trustees

<b>Signature(s)</b>		
<b>Full name(s)</b>	Lydia Hirst	Allison Watson
<b>Position (eg Secretary, Chair, etc)</b>	Chair	Secretary
<b>Date</b>	16th September 2022	

<b>TITLE</b>	Annual Trustee report 2022 FINAL_signed
<b>FILE NAME</b>	Annual Trustee report 2022 FINAL.pdf
<b>DOCUMENT ID</b>	6ab510e2b461807f8429f5f187eadcba6fccbb24
<b>AUDIT TRAIL DATE FORMAT</b>	DD / MM / YYYY
<b>STATUS</b>	● Signed

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## Document history



SENT

**16 / 09 / 2022**

08:03:58 UTC

Sent for signature to Lydia Hirst  
 (lydia@ring20researchsupport.co.uk) from  
 allison@ring20researchsupport.co.uk  
 IP: 104.248.169.17



VIEWED

**16 / 09 / 2022**

10:06:52 UTC

Viewed by Lydia Hirst (lydia@ring20researchsupport.co.uk)  
 IP: 217.192.101.2



SIGNED

**16 / 09 / 2022**

10:07:54 UTC

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 IP: 217.192.101.2



COMPLETED

**16 / 09 / 2022**

10:07:54 UTC

The document has been completed.

# **RING20 RESEARCH AND SUPPORT UK CIO**

Charity number 1165651

**FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31st MARCH 2022**





# RING20 RESEARCH AND SUPPORT UK CIO

## CONTENTS FOR THE YEAR ENDED 31 MARCH 2022

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	Page
Receipts and payments account	1
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Notes to the accounts	3-4
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---

# RING20 RESEARCH AND SUPPORT UK CIO

## RECEIPTS AND PAYMENTS ACCOUNT FOR THE YEAR ENDED 31 MARCH 2022

---

	Note	Unrestricted Fund £	Restricted Fund £	2022 Total £	2021 Total £
<b>Receipts:</b>					
Donations	2	3,708	-	3,708	5,301
Sponsorship/grant funding		300	23,500	23,800	34,367
Member fundraising		2,911	10,047	12,958	4,136
Interest received		-	10	10	35
<b>Total receipts</b>		<b>6,919</b>	<b>33,557</b>	<b>40,476</b>	<b>43,839</b>
<b>Payments:</b>					
<b>Charitable payments</b>					
Charitable activities	3	7,772	24,682	32,453	12,779
<b>Total payments</b>		<b>7,772</b>	<b>24,682</b>	<b>32,453</b>	<b>12,779</b>
<b>Net receipts/(payments)</b>		<b>(853)</b>	<b>8,875</b>	<b>8,022</b>	<b>31,060</b>
<b>Transfers between funds</b>		4,357	(4,357)	-	-
<b>Net of receipts/(payments)</b>		<b>3,504</b>	<b>4,518</b>	<b>8,022</b>	<b>31,060</b>
<b>Cash funds brought forward</b>	6	11,902	106,397	118,300	87,240
<b>Cash funds carried forward</b>	6	<b>15,407</b>	<b>110,916</b>	<b>126,323</b>	<b>118,301</b>

The notes on page 3 - 4 form part of these accounts

# RING20 RESEARCH AND SUPPORT UK CIO

## STATEMENT OF ASSETS AND LIABILITIES AS AT 31 MARCH 2022

	Notes	2022 £	2021 £
<b><u>Cash funds</u></b>			
Current account		4,748	51,194
Deposit account		121,574	67,106
		<u>126,323</u>	<u>118,300</u>
<b><u>Represented by</u></b>			
Unrestricted funds	6	15,407	11,902
Restricted funds	6	110,916	106,397
		<u>126,323</u>	<u>118,300</u>
<b><u>Non-monetary assets/liabilities</u></b>			
		2022 £	2021 £
<b><u>Fixed assets</u></b>			
Equipment	4	-	-
		<u>-</u>	<u>-</u>
<b><u>Current assets</u></b>			
Debtors		752	-
		<u>752</u>	<u>-</u>
<b><u>Liabilities</u></b>			
Independent examination fee		250	250
Other creditors		378	890
		<u>628</u>	<u>1,140</u>
Total assets less liabilities		<u>124</u>	<u>(1,140)</u>

These accounts were approved by the Trustees, and signed on their behalf by:

Treasurer 

Date: 05/10/2022

Name: Kim Parks

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

### 1. Accounting policies

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement on 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) -(Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

1.1 These accounts are prepared on a receipts and payments basis.

### 2. Donations

	Unrestricted Fund £	Restricted Fund £	Total 2022 £	Total 2021 £
General donations	3,708	-	3,708	5,301
	<u>3,708</u>	<u>-</u>	<u>3,708</u>	<u>5,301</u>

### 3. Expenditure from charitable activities

	Unrestricted Fund £	Restricted Fund £	Total 2022 £	Total 2021 £
Other project costs	-	-	-	64
Cost of sales	180	-	180	130
Attending conferences & events	316	-	316	118
Hosting conferences & events	499	1,062	1,561	-
Literature & materials	271	4,534	4,805	5,725
Website & emails	142	3,036	3,178	1,257
Accountancy, examination & audit	250	-	250	-
Wages	-	2,274	2,274	3,045
Director salaries	4,000	12,392	16,392	-
Office expenditure	27	-	27	13
Bank charges	154	-	154	59
Computer costs	529	833	1,362	940
DBS checks	-	-	-	12
Insurances	453	-	453	444
Postage	66	-	66	828
Subscriptions	188	-	188	212
Telephone	389	-	389	20
Training	308	550	858	(88)
	<u>7,772</u>	<u>24,682</u>	<u>32,453</u>	<u>12,779</u>

### 4. Equipment

	Total 2022 £	Total 2021 £
Website development	-	-
Computer hardware	-	-
	<u>-</u>	<u>-</u>

The net book value in 2021 was reduced to £Nil as depreciation has been applied and corrected due to depreciation not being applied at all since the purchase of the items. They have no value.

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

6. Funds analysis	Balance at 01/04/21 £	Incoming Funds £	Expended Funds £	Transfers in/out £	Balance at 31/03/22 £
<b>Unrestricted</b>					
General fund	10,230	-	-	(10,230)	0
Running costs	(6,801)	2,509	(3,556)	9,260	1,412
Fundraising	6,097	4,410	(215)	(4,770)	5,522
<b>Designated funds</b>					
General designated	(766)	-	-	766	-
Salaries	-	-	(4,000)	12,473	8,473
Comic workshop	3,142	-	-	(3,142)	-
	<u>11,903</u>	<u>6,919</u>	<u>(7,772)</u>	<u>4,357</u>	<u>15,407</u>
<b>Restricted funds</b>					
COVID Cadent	2,000	-	(2,000)	-	-
COVID TNLF	5,815	1,000	(3,824)	(2,991)	-
Family Conference	12,457	12,500	473	-	25,430
Illumina Research Project	17,263	-	(15,342)	-	1,921
Research Funds	67,467	10,057	-	29	77,553
Mental Health Workshops	-	10,000	(3,987)	-	6,013
Social Media Support	1,395	-	-	(1,395)	-
<b>Total restricted funds</b>	<u>106,397</u>	<u>33,557</u>	<u>(24,681)</u>	<u>(4,357)</u>	<u>110,916</u>
<b>Totals</b>	<u>118,300</u>	<u>40,476</u>	<u>(32,452)</u>	<u>-</u>	<u>126,323</u>

### 7. Trustee payments

During 2022, one trustee received remunerations of £15,999.96 (2021: £2,666.66) as wages during the year.

### 8. Related party transactions

There were no related party transactions during the year.

### 9. Going concern

The charity is operating on a going concern basis.

### 10. Key management personnel

No staff have earned more than £60,000 during the year.

# RING20 RESEARCH AND SUPPORT UK CIO

## INDEPENDENT EXAMINER'S REPORT FOR THE YEAR ENDED 31 MARCH 2022

---

I report on the accounts of Ring20 Research and Support UK CIO for the year ended 31 March 2022 which are set out on pages one to four.

### **Respective responsibilities of trustees and examiner**

The Charity's Trustees are responsible for the preparation of the accounts. The Charity's Trustees consider that an audit is not required for this year (under section 144 (2) of the Charities Act 2011 (The Act) but that an independent examination is needed.

It is my responsibility to:

- Examine the accounts under section 145 of the Charities Act;
- To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 145(5)(b) of the Charities Act); and
- To state whether particular matters have come to my attention.

### **Basis of independent examiner's Statement**

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the Charity and a comparison of the accounts presented with those records. It also includes considerations of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently I do not express an audit opinion on the view given by the accounts.

### **Independent examiner's statement**

In connection with my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or

I have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Shelley-Marie Rudling FMAAT AATQB for and on behalf of:

Community360, Winsley's House  
High Street, Colchester, Essex



Date 13<sup>th</sup> October 2022



# **RING20 RESEARCH AND SUPPORT UK CIO**

Charity number 1165651

**FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31st MARCH 2022**





# RING20 RESEARCH AND SUPPORT UK CIO

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---

# RING20 RESEARCH AND SUPPORT UK CIO

## RECEIPTS AND PAYMENTS ACCOUNT FOR THE YEAR ENDED 31 MARCH 2022

---

	Note	Unrestricted Fund £	Restricted Fund £	2022 Total £	2021 Total £
<b>Receipts:</b>					
Donations	2	3,708	-	3,708	5,301
Sponsorship/grant funding		300	23,500	23,800	34,367
Member fundraising		2,911	10,047	12,958	4,136
Interest received		-	10	10	35
<b>Total receipts</b>		<b>6,919</b>	<b>33,557</b>	<b>40,476</b>	<b>43,839</b>
<b>Payments:</b>					
<b>Charitable payments</b>					
Charitable activities	3	7,772	24,682	32,453	12,779
<b>Total payments</b>		<b>7,772</b>	<b>24,682</b>	<b>32,453</b>	<b>12,779</b>
<b>Net receipts/(payments)</b>		<b>(853)</b>	<b>8,875</b>	<b>8,022</b>	<b>31,060</b>
<b>Transfers between funds</b>		4,357	(4,357)	-	-
<b>Net of receipts/(payments)</b>		<b>3,504</b>	<b>4,518</b>	<b>8,022</b>	<b>31,060</b>
<b>Cash funds brought forward</b>	6	11,902	106,397	118,300	87,240
<b>Cash funds carried forward</b>	6	<b>15,407</b>	<b>110,916</b>	<b>126,323</b>	<b>118,301</b>

The notes on page 3 - 4 form part of these accounts

# RING20 RESEARCH AND SUPPORT UK CIO

## STATEMENT OF ASSETS AND LIABILITIES AS AT 31 MARCH 2022

	Notes	2022 £	2021 £
<b><u>Cash funds</u></b>			
Current account		4,748	51,194
Deposit account		121,574	67,106
		<u>126,323</u>	<u>118,300</u>
<b><u>Represented by</u></b>			
Unrestricted funds	6	15,407	11,902
Restricted funds	6	110,916	106,397
		<u>126,323</u>	<u>118,300</u>
<b><u>Non-monetary assets/liabilities</u></b>			
		2022 £	2021 £
<b><u>Fixed assets</u></b>			
Equipment	4	-	-
		-	-
<b><u>Current assets</u></b>			
Debtors		752	-
		<u>752</u>	-
<b><u>Liabilities</u></b>			
Independent examination fee		250	250
Other creditors		378	890
		<u>628</u>	<u>1,140</u>
Total assets less liabilities		<u>124</u>	<u>(1,140)</u>

These accounts were approved by the Trustees, and signed on their behalf by:

Treasurer 

Date: 05/10/2022

Name: Kim Parks

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

### 1. Accounting policies

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement on 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) -(Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

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### 2. Donations

	Unrestricted Fund £	Restricted Fund £	Total 2022 £	Total 2021 £
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### 3. Expenditure from charitable activities

	Unrestricted Fund £	Restricted Fund £	Total 2022 £	Total 2021 £
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Cost of sales	180	-	180	130
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Literature & materials	271	4,534	4,805	5,725
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Insurances	453	-	453	444
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Telephone	389	-	389	20
Training	308	550	858	(88)
	<u>7,772</u>	<u>24,682</u>	<u>32,453</u>	<u>12,779</u>

### 4. Equipment

	Total 2022 £	Total 2021 £
Website development	-	-
Computer hardware	-	-
	<u>-</u>	<u>-</u>

The net book value in 2021 was reduced to £Nil as depreciation has been applied and corrected due to depreciation not being applied at all since the purchase of the items. They have no value.

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

6. Funds analysis	Balance at 01/04/21 £	Incoming Funds £	Expended Funds £	Transfers in/out £	Balance at 31/03/22 £
<b>Unrestricted</b>					
General fund	10,230	-	-	(10,230)	0
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Fundraising	6,097	4,410	(215)	(4,770)	5,522
<b>Designated funds</b>					
General designated	(766)	-	-	766	-
Salaries	-	-	(4,000)	12,473	8,473
Comic workshop	3,142	-	-	(3,142)	-
	<u>11,903</u>	<u>6,919</u>	<u>(7,772)</u>	<u>4,357</u>	<u>15,407</u>
<b>Restricted funds</b>					
COVID Cadent	2,000	-	(2,000)	-	-
COVID TNLF	5,815	1,000	(3,824)	(2,991)	-
Family Conference	12,457	12,500	473	-	25,430
Illumina Research Project	17,263	-	(15,342)	-	1,921
Research Funds	67,467	10,057	-	29	77,553
Mental Health Workshops	-	10,000	(3,987)	-	6,013
Social Media Support	1,395	-	-	(1,395)	-
<b>Total restricted funds</b>	<u>106,397</u>	<u>33,557</u>	<u>(24,681)</u>	<u>(4,357)</u>	<u>110,916</u>
<b>Totals</b>	<u>118,300</u>	<u>40,476</u>	<u>(32,452)</u>	<u>-</u>	<u>126,323</u>

### 7. Trustee payments

During 2022, one trustee received remunerations of £15,999.96 (2021: £2,666.66) as wages during the year.

### 8. Related party transactions

There were no related party transactions during the year.

### 9. Going concern

The charity is operating on a going concern basis.

### 10. Key management personnel

No staff have earned more than £60,000 during the year.

# RING20 RESEARCH AND SUPPORT UK CIO

## INDEPENDENT EXAMINER'S REPORT FOR THE YEAR ENDED 31 MARCH 2022

---

I report on the accounts of Ring20 Research and Support UK CIO for the year ended 31 March 2022 which are set out on pages one to four.

### **Respective responsibilities of trustees and examiner**

The Charity's Trustees are responsible for the preparation of the accounts. The Charity's Trustees consider that an audit is not required for this year (under section 144 (2) of the Charities Act 2011 (The Act) but that an independent examination is needed.

It is my responsibility to:

- Examine the accounts under section 145 of the Charities Act;
- To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 145(5)(b) of the Charities Act); and
- To state whether particular matters have come to my attention.

### **Basis of independent examiner's Statement**

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the Charity and a comparison of the accounts presented with those records. It also includes considerations of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently I do not express an audit opinion on the view given by the accounts.

### **Independent examiner's statement**

In connection with my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or

I have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Shelley-Marie Rudling FMAAT AATQB for and on behalf of:

Community360, Winsley's House  
High Street, Colchester, Essex



Date 13<sup>th</sup> October 2022



**RING20 RESEARCH AND SUPPORT UK CIO**

England & Wales - Charity number 1165651

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# Accounts

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# Trustees' Annual Report for the period

<b>From</b>	Period start date			<b>To</b>	Period end date		
	Day 19	Month February	Year 2020		Day 31	Month March	Year 2021

## 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**

26 Headley Chase

Brentwood

Essex

**Postcode**

CM14 5BN

### 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	Allison Watson	Secretary		
2	Donald Gordon	Chairperson	Apr 20 to Oct 20	
3	Kim Parks	Treasurer		
4	Claire Sullivan	Fundraiser		
5	Chris Sullivan	Fundraiser		
6	Lydia Hirst	Trustee	Oct 20 onwards	
7	Neil White	Chairperson	Oct 20 onwards	

### 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
Grant and Fundraising Consultant	Gemma Underwood	

### 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.

Trustees operate in their specific areas of activity but consult on all significant matters of policy formulation, family support and methods of communication about Ring20 information services to medical professionals. Trustee training has continued as needed related to specific areas of activity.. Two new board members were recruited in September 2020, one as Chair and one as Trustee. The previous Chair stepped down in Nov 2020 at the AGM.

The Medical Advisory Board remains in place with Prof Sameer Zuberi taking over from Dr Sophia Varadkar as Ring20 Chief Medical Advisor.

The charity is a member of:

- Brentwood CVS
- Genetic Alliance UK
- Neurological Alliance
  - CEO represents us in the Rare Disease sub-group
- EURORDIS
  - CEO is a EURORDIS volunteer
- Rare Revolution Magazine
- International Bureau for Epilepsy (IBE)
- Rare Epilepsy Network (REN)
- Commission for Neurodevelopmental CNVs

and benefits from services provided by EURORDIS, Findacure, CRDN including mentoring, training and networking opportunities.

Our CEO participates in the British Paediatric Neurology Association (BPNA) charities forum and has recently co-founded the UK Rare Epilepsies Network (UK RET) comprising patient organisations across the UK representing individuals and families living with rare and complex epilepsies.

Our CEO continues to provide a significant contribution to EpiCARE the European Reference Network (ERN) for rare and complex epilepsies sitting on the steering committee and co-leads the European Patient Advocacy Group (ePAG) for the ERN. Allison's role continues to develop and broaden constantly bringing the patient family perspective into discussions.

Further our CEO has input to the new UK Rare Disease Framework Action Plan for England.

The charity has updated its insurance with an international underwriter to cover normal risks and operates the following policies: child protection, data privacy, risk management and volunteer, published on our website.

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

To support families, individuals and medical professionals who are affected by, or come into contact with, Ring Chromosome 20 Syndrome.

**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.

The charity provides a support group for individuals and families affected by the condition. We aim to provide the latest information on the condition to families and professionals via our website, regular enews and social media.

We continue to work on raising both public awareness and education amongst key medical professionals throughout the UK and Europe so they can relate to the signs, symptoms and medical diagnosis of r(20) syndrome. Speaking at and/or hosting an exhibition stand (in-person or virtually) at medical and scientific conferences provides opportunities to fulfil our aims and objectives whilst developing strategic partnerships with research facilities, medical institutions and like-minded charitable bodies.

The Charity has raised funds to pay for research to be undertaken by Glasgow University Hospital into a Natural History study and registry for those currently diagnosed with the disease. Another research study is proposed in 2021-22 in partnership with Illumina and Glasgow University Hospital, with patients supported by Ring20, to improve the diagnostic journey.

The Trustees consider the charity's activities are wholly in the public interest and designed to benefit all those who suffer from r(20), their families and medical professionals dealing with this debilitating condition, in line with the Charity's Commission guidance on 'public benefit'.

**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 all their volunteers for their support throughout the year: Dave Soderquest (to Jun 20), Audrey Everiss (to Jun 20), Samuel Dwinell (Jun-Oct 20), Vydia Kamath (Jun—Nov 20), Clare Carter (Aug-Mar 21), Dale Ward, Jon Dunn.

Special mention should go to our newest volunteers recruited during the period:

- Jake Ogilvie (Digital)
- Kallif Garlicki (Support)
- Laura Giordana (Comms)
- Ian Allen (Accounts)
- Clara Tang (Research)
- Shahid Mughal (Operations Management)
- Ana Vieitez (Funding)

**Summary of the main achievements of the charity during the year**

During the period a number of aims were achieved:

The website was updated for all topical information on the condition and fundraising events, and regular enews and biannual newsletters issued. Phone and email support provided to individuals and families of those with the condition.

The pandemic curtailed any in-person events e.g., we had to postpone our planned 2<sup>nd</sup> ever Families Conference event. Fundraising events were significantly reduced. However, we utilised the opportunity to reach out digitally to our members, supporters and wider audience by introducing and/or attending virtual events.

We utilised funding to take on an apprentice to help with our digital communications.

**Information Comics**

We distributed r(20) information comics free of charge to over 100 families and their medical teams across the world.

**Coffee and Chat**

In response to the pandemic, we initiated regular online Coffee and Chat sessions via Zoom for our families to meetup online and talk in a safe, supportive environment. This is something we will continue as our member families are widely dispersed across the globe and virtual meet-ups are sometimes the only way that families can connect.

**Natural History/Biomarker research study**

The commencement of the proposed Natural History/Biomarker research study with Professor Sameer Zuberi from Glasgow's Royal Hospital for Children whilst previously approved by the Medical Advisory Board has, as with all non-COVID related research projects, been postponed due to the pandemic.

Illumina study

**Conferences/Events attended:**

- ECRD Stockholm – presentation and abstract submission (May 19)
- Epilepsy Foundation Virtual Pipeline Conference – presentation (Aug 20)
- World Orphan Drug Congress USA (Aug 20) - panel speaker
- CRDN RareFest20 – virtual exhibition stand (Sept 2020)
- Genetic Alliance AGM (Oct 20)
- Findacure Virtual Rare Disease Showcase – presentation (Nov 20)
- BPNA UK Annual Conference – virtual exhibition stand and Paediatric Neurology Charities Meeting (Jan 21)
- Rare Disease Day Parliamentary Reception - online (Feb 21)

**Training/mentoring:**

Connect4Children workshop (Sep 20)

CONCORD workshop (Sep 20)

CEO attended Rare Resilience workshops offered by Genetic Alliance UK

Apprenticeship Training facilitated by Aspire2Learn

**Brief statement of the charity's policy on reserves**

The charity receives funding for specific purposes which are restricted funds – these are not available for expenditure on other purposes. 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 a general reserve in the range £5,500 - £6,500 to cover unfunded committed costs for the next 6 months.

Our general reserve at 31 March 2021 was £11,902 (of which £4,072 has been designated for salaries), leaving £7,830 of Free Reserves which is slightly in excess of policy. The Board will review the policy in Q4 2021.

**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.

During the period to 31 March 2021 the charity raised £43,839 through multiple income streams including Interest Received of £35 (0.001%):

**Member Fundraising £2,042 (5%)**

- |                           |        |
|---------------------------|--------|
| ➤ Middleton family raffle | £ 636  |
| ➤ Body shop raffle        | £ 100  |
| ➤ Easter Egg raffle       | £ 60   |
| ➤ Collection pot V Ford   | £ 55   |
| ➤ Facebook Fundraisers    | £1,191 |

**Donations £5,301 (12%)****Members**

- |  |        |
|--|--------|
| ➤ Regular Donations                      | £ 192  |
| ➤ Ad hoc (various)                       | £1,062 |
| ➤ Overseas                               | £ 0    |
| ➤ Fundraising Fortnight Raffle/donations | £1,292 |

**Corporate**

- |                                 |        |
|---------------------------------|--------|
| ➤ Truflow Marine                | £1,136 |
| ➤ Shared Services Connected Ltd | £1,000 |
| ➤ Western Power                 | £ 300  |
| ➤ NRG Collective                | £ 30   |

**Online**

- Easyfundraising, Fit4Change, AmazonSmile, Essex Lottery

**Grant Funding £14,387 (28%)**

- |   |        |
|---|--------|
| ➤ Pettigrew Charitable Trust Unrestricted | £1,000 |
| ➤ Genetic Disorders UK Restricted         | £3,417 |
| ➤ TNLF COVID response Restricted          | £7,950 |
| ➤ Cadent COVID response Restricted        | £2,000 |

**Corporate Sponsorship £20,000 (46%)**

- |                |         |
|----------------|---------|
| ➤ Illumina Inc | £20,000 |
|----------------|---------|

**HMRC gift aid including GASDS £2,094 (5%)**

The charity spent £13,474 of which the main items of expenditure in support of its objectives were:

- Producing/distributing comics £5,275
- Staff salaries £3,192
- Website £1,257
- Computer costs £1,132

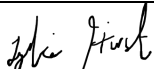

Our Ring20 patient information comics have been a huge success with our patient families and healthcare professionals alike, across the world, providing insight into living with r(20) syndrome.

## Section F Other optional information

## Section G Declaration

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

Signed on behalf of the charity's trustees

<b>Signature(s)</b>		
<b>Full name(s)</b>	Lydia Hirst	Allison Watson
<b>Position (eg Secretary, Chair, etc)</b>	Chair	Secretary
<b>Date</b>	2 <sup>nd</sup> December 2021	

<b>TITLE</b>	Annual Trustee report 2021 Final_signed
<b>FILE NAME</b>	Annual Trustee report 2021 Final.pdf
<b>DOCUMENT ID</b>	1b924ed76971fd5ed4a18530b955a56d34a75619
<b>AUDIT TRAIL DATE FORMAT</b>	DD / MM / YYYY
<b>STATUS</b>	● Completed

## Document history



SENT

**03 / 12 / 2021**

11:30:33 UTC

Sent for signature to Lydia Hirst  
 (lydia@ring20researchsupport.co.uk) from  
 allison@ring20researchsupport.co.uk  
 IP: 92.20.23.140



VIEWED

**06 / 12 / 2021**

16:01:49 UTC

Viewed by Lydia Hirst (lydia@ring20researchsupport.co.uk)  
 IP: 82.39.102.177



SIGNED

**06 / 12 / 2021**

16:02:21 UTC

Signed by Lydia Hirst (lydia@ring20researchsupport.co.uk)  
 IP: 82.39.102.177



COMPLETED

**06 / 12 / 2021**

16:02:21 UTC

The document has been completed.

# **RING20 RESEARCH AND SUPPORT UK CIO**

Charity number 1165651

## **FINANCIAL STATEMENTS FOR THE YEAR ENDED 31st MARCH 2021**



# RING20 RESEARCH AND SUPPORT UK CIO

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# RING20 RESEARCH AND SUPPORT UK CIO

## RECEIPTS AND PAYMENTS ACCOUNT FOR THE YEAR ENDED 31 MARCH 2021

---

	Note	Unrestricted Fund £	Restricted Fund £	2021 Total £	2020 Total £
<b>Receipts:</b>					
Donations	2	5,301	-	5,301	12,049
Sponsorship/grant funding		1,000	33,367	34,367	6,904
Member Fundraising		2,434	1,701	4,136	5,778
Interest received		-	35	35	133
<b>Total receipts</b>		<b>8,735</b>	<b>35,103</b>	<b>43,839</b>	<b>24,864</b>
<b>Payments:</b>					
<b>Charitable payments</b>					
Charitable activities	3	7,907	4,872	12,779	21,503
<b>Total payments</b>		<b>7,907</b>	<b>4,872</b>	<b>12,779</b>	<b>21,503</b>
<b>Net of receipts/(payments)</b>		<b>828</b>	<b>30,231</b>	<b>31,060</b>	<b>3,361</b>
<b>Cash funds brought forward</b>	6	11,074	76,166	87,240	83,879
<b>Cash funds carried forward</b>	6	<b>11,902</b>	<b>106,397</b>	<b>118,300</b>	<b>87,240</b>

The notes on page 3 - 4 form part of these accounts


# RING20 RESEARCH AND SUPPORT UK CIO

## STATEMENT OF ASSETS AND LIABILITIES AS AT 31 MARCH 2021

---

	Notes	2021 £	2020 £
<b><u>Cash Funds</u></b>			
Current account		51,194	20,169
Deposit account		67,106	67,071
		<u>118,300</u>	<u>87,240</u>
<b><u>Represented by</u></b>			
Unrestricted funds	6	11,902	11,074
Restricted funds	6	106,397	76,166
		<u>118,300</u>	<u>87,240</u>
<b><u>Fixed assets</u></b>			
Equipment	4	-	4,124
		-	4,124
<b><u>Liabilities</u></b>			
Independent examination fee		250	-
Other creditors		890	-
		<u>1,140</u>	-
Total Assets less Liabilities		<u>(1,140)</u>	<u>4,124</u>

These accounts were approved by the Trustees, and signed on their behalf by:

Treasurer   
\_\_\_\_\_

Date: 3rd December 2021

Name: Kim Parks

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

### 1. Accounting policies

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement on 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) -(Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

1.1 These accounts are prepared on a receipts and payments basis.

### 2. Donations

	Unrestricted Fund £	Restricted Fund £	Total 2021 £	Total 2020 £
General donations	5,301	-	5,301	12,049
	<u>5,301</u>	<u>-</u>	<u>5,301</u>	<u>12,049</u>

### 3. Charitable activities

	Unrestricted Fund £	Restricted Fund £	Total 2021 £	Total 2020 £
Other project costs	64	-	64	75
Cost of sales	130	-	130	-
Attending conferences & events	118	-	118	658
Fundraising merchandise	-	-	-	571
Hosting conferences & events	-	-	-	5,969
Literature & materials	5,673	52	5,725	3,500
Website & emails	8	1,249	1,257	7,615
Accountancy, examination & audit	-	-	-	1,200
Wages	-	3,045	3,045	-
Office expenditure	13	-	13	-
Bank charges	59	-	59	-
Computer costs	414	526	940	612
DBS checks	12	-	12	124
Insurances	444	-	444	447
Postage	828	-	828	75
Subscriptions	212	-	212	327
Telephone	20	-	20	190
Training	(88)	-	(88)	140
	<u>7,907</u>	<u>4,872</u>	<u>12,779</u>	<u>21,503</u>

### 4. Equipment

	Total 2021 £	Total 2020 £
Website development	-	3,154
Computer hardware	-	970
	<u>-</u>	<u>4,124</u>

The net book value in 2021 has reduced to £Nil as depreciation has been applied and corrected due to depreciation not being applied at all since the purchase of the items. They have no value.

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

---

<b>6. Funds analysis</b>	<b>Balance at 01/04/20 £</b>	<b>Incoming Funds £</b>	<b>Expended Funds £</b>	<b>Transfers in/out £</b>	<b>Balance at 31/03/21 £</b>
<b>Unrestricted</b>					
General Fund	10,233	-	(3)	-	<b>10,230</b>
Running costs	(6,491)	2,573	(2,883)	-	<b>(6,801)</b>
Fundraising	(65)	6,162	-	-	<b>6,097</b>
<b>Designated funds</b>					
General designated	(673)	-	(93)	-	<b>(766)</b>
Comic Workshop	8,070	-	(4,928)	-	<b>3,142</b>
	<b>11,074</b>	<b>8,736</b>	<b>(7,907)</b>	<b>-</b>	<b>11,903</b>
<b>Restricted funds</b>					
COVID Cadent	-	2,000	-	-	<b>2,000</b>
COVID TNLF	-	7,950	(2,135)	-	<b>5,815</b>
Family Conference	7,972	4,485	-	-	<b>12,457</b>
Illumina Research Project	-	20,000	(2,737)	-	<b>17,263</b>
Research Funds	66,799	668	-	-	<b>67,467</b>
Social Media Support	1,395	-	-	-	<b>1,395</b>
<b>Total restricted funds</b>	<b>76,166</b>	<b>35,103</b>	<b>(4,872)</b>	<b>-</b>	<b>106,397</b>
<b>TOTALS</b>	<b>87,240</b>	<b>43,839</b>	<b>(12,779)</b>	<b>-</b>	<b>118,300</b>

### 7. Trustee payments

During 2021, no trustees received any payments from the charity.

### 8. Related party transactions

A trustee received remuneration for their CEO role (Allison Watson) for a total of £2666.66 for 2021.

### 9. Going concern

The charity is operating on a going concern basis.

### 10. Key management personnel

No staff (self employed) have earned more than £60,000 during the year.

# **RING20 RESEARCH AND SUPPORT UK CIO**

Charity number 1165651

**FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31st MARCH 2021**





# RING20 RESEARCH AND SUPPORT UK CIO

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# RING20 RESEARCH AND SUPPORT UK CIO

## RECEIPTS AND PAYMENTS ACCOUNT FOR THE YEAR ENDED 31 MARCH 2021

---

	Note	Unrestricted Fund £	Restricted Fund £	2021 Total £	2020 Total £
<b>Receipts:</b>					
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Sponsorship/grant funding		1,000	33,367	34,367	6,904
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Charitable activities	3	7,907	4,872	12,779	21,503
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The notes on page 3 - 4 form part of these accounts

# RING20 RESEARCH AND SUPPORT UK CIO

## STATEMENT OF ASSETS AND LIABILITIES AS AT 31 MARCH 2021

	Notes	2021 £	2020 £
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		<u>118,300</u>	<u>87,240</u>
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Restricted funds	6	106,397	76,166
		<u>118,300</u>	<u>87,240</u>
<b>Fixed assets</b>			
Equipment	4	-	4,124
		-	4,124
<b>Liabilities</b>			
Independent examination fee		250	-
Other creditors		890	-
		<u>1,140</u>	-
Total Assets less Liabilities		<u>(1,140)</u>	<u>4,124</u>

These accounts were approved by the Trustees, and signed on their behalf by:

Treasurer 

Date: 3rd December 2021

Name: Kim Parks

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

### 1. Accounting policies

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General donations	5,301	-	5,301	12,049
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Other project costs	64	-	64	75
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Office expenditure	13	-	13	-
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### 4. Equipment

	Total 2021 £	Total 2020 £
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Computer hardware	-	970
	<u>-</u>	<u>4,124</u>

The net book value in 2021 has reduced to £Nil as depreciation has been applied and corrected due to depreciation not being applied at all since the purchase of the items. They have no value.

# RING20 RESEARCH AND SUPPORT UK CIO

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

6. Funds analysis	Balance at 01/04/20 £	Incoming Funds £	Expended Funds £	Transfers in/out £	Balance at 31/03/21 £
<b>Unrestricted</b>					
General Fund	10,233	-	(3)	-	10,230
Running costs	(6,491)	2,573	(2,883)	-	(6,801)
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<b>Designated funds</b>					
General designated	(673)	-	(93)	-	(766)
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	<b>11,074</b>	<b>8,736</b>	<b>(7,907)</b>	<b>-</b>	<b>11,903</b>
<b>Restricted funds</b>					
COVID Cadent	-	2,000	-	-	2,000
COVID TNLF	-	7,950	(2,135)	-	5,815
Family Conference	7,972	4,485	-	-	12,457
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Social Media Support	1,395	-	-	-	1,395
<b>Total restricted funds</b>	<b>76,166</b>	<b>35,103</b>	<b>(4,872)</b>	<b>-</b>	<b>106,397</b>
<b>TOTALS</b>	<b>87,240</b>	<b>43,839</b>	<b>(12,779)</b>	<b>-</b>	<b>118,300</b>

### 7. Trustee payments

During 2021, no trustees received any payments from the charity.

### 8. Related party transactions

A trustee received remuneration for their CEO role (Allison Watson) for a total of £2666.66 for 2021.

### 9. Going concern

The charity is operating on a going concern basis.

### 10. Key management personnel

No staff (self employed) have earned more than £60,000 during the year.

# RING20 RESEARCH AND SUPPORT UK CIO

## INDEPENDENT EXAMINER'S REPORT FOR THE YEAR ENDED 31 MARCH 2021

---

I report on the accounts of Ring20 Research and Support UK CIO for the year ended 31 March 2021 which are set out on pages 2 to 4.

### **Respective responsibilities of trustees and examiner**

The Charity's Trustees are responsible for the preparation of the accounts. The Charity's Trustees consider that an audit is not required for this year (under section 144 (2) of the Charities Act 2011 (The Act) but that an independent examination is needed.

It is my responsibility to:

- Examine the accounts under section 145 of the Charities Act,
- To follow the procedures laid down in the General Directions given by the Charity Commissioners (under section 145(5)(b) of the Charities Act, and
- To state whether particular matters have come to my attention.

### **Basis of independent examiner's Statement**

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the Charity and a comparison of the accounts presented with those records. It also includes considerations of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently I do not express an audit opinion on the view given by the accounts.

### **Independent examiner's statement**


In the course of my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of the accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair' view which is not a matter considered as part of an independent examination.

I have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Shelley-Marie Rudling FMAAT AATQB for and on behalf of;  
Community360

Winsley's House, High Street, Colchester, Essex.



Date 8<sup>th</sup> December  
2021