



Trustees' Annual Report for the period

From	Period start date			To	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 2nd 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%)

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|---------------------------|--------|
| ➤ 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

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Section G Declaration

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

Signed on behalf of the charity's trustees

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