



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	Day 19	Month February	Year 2019		Day 31	Month March	Year 2020

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		
3	Sophia Varadkar	Medical Advisor		
4	Claire Sullivan	Fundraiser		
5	Chris Sullivan	Fundraiser		

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
Treasurer	Kim Parks	27 Kirkham Apartments, 43 Linton Road, Barking, Essex, IG11 8FT
Grant and Fundraising Officer (stepped down June 19)	Kim Alliston	
Grant and Fundraising Consultant	Gemma Underwood	

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

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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.

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 and the board of trustees remain the same.

The Medical Advisory Board remains in place with no changes during this financial period with oversight from Dr Sophia Varadkar Ring20 Medical Advisor.

The charity is a member of:

- Brentwood CVS
- Genetic Alliance UK
- Neurological Alliance
 - Secretary represents us in the Rare Disease sub-group
- EURORDIS
 - Secretary is a EURORDIS volunteer
- Rare Revolution Magazine

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

Our secretary participates in the British Paediatric Neurology Association (BPNA) charities forum, which this year has included updates on access to Cannabis Based Medicinal Products (CBMP).

Our Secretary 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-leading their European Patient Advisory Group (EPAG). Allison's role continues to develop and broaden constantly bringing the patient family perspective into discussions. Initiatives benefitting Ring20 include developing information leaflets for patient families and healthcare professionals, drafting an r(20) Patient Journey to identify patient unmet needs and updating Orphanet.

Ring20 has worked with NCARDRS to launch a self-registration pilot in England for r(20) patients.

Ring20 has commenced an application to National Institute for Health Research (NIHR) (Bioresource Unit) to develop a ring chromosome patient cohort.

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. Hosting an exhibition stand 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 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: Kim Parks, Dawn Gray, Dale Ward, Jon Dunn.

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

- Nik Singh – Events Coordinator May 19 – Jan 20
- Dave Soderquest - Project /Events Manager Oct 19 – Jun 20
- Audrey Everiss – Admin Officer Jan 20 – Jun 20

Nik and Dave made a significant contribution to make our Comic Workshop and Big Give Christmas Challenge Campaign extraordinarily successful.

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.

KDT Study

In collaboration with PLRH the charity undertook a research study comprising 2x surveys: 1x patient families, 1x healthcare professionals and hosted a workshop to review the results in May 2019. A manuscript was published in the broadly read medical professional publication *Epilepsia* online on “**Assessing the role of ketogenic dietary therapy in ring chromosome 20 syndrome: a patient led approach**” and an abstract poster presented at the annual British Paediatric Neurology Association (BPNA) annual meeting attended by Chair Donald Gordon and Allison Watson.

Patient Information Booklets (Comic format)

A project was undertaken to produce a Patient Information Booklet, commencing with a workshop (Nov 2019) with the output from workshop producing a youth project to develop comic workbooks for publication and distribution to medical professionals, families, patient groups and support educational workers. The final comics will be distributed FREE to member families and interested healthcare professionals in Q4 2020.

The Big Give Christmas Challenge Campaign 2019

Ring20 ran a highly successful fundraising campaign running from the summer months and culminating in a final week of online donations securing £8,607 with £1,068 of gift aid still to be claimed.

Natural History/Biomarker research study

The proposed Natural History/Biomarker research study with Professor Sameer Zuberi from Glasgow’s Royal Hospital for Children has been approved by the Medical Advisory Board but as with all research projects commencement of the study has been postponed due to COVID19.

Conferences/Events attended:

- Genomic Medicine Masters Students – speaker (May 19)
- ECRD Bucharest (May 19)
- Sano Genetics: Demystifying Genomics for Patient Registries – speaker (Jul 19)
- CRDN Rare Summit - panel speaker, poster, BBC News interview (Sept 2019)
- Genetic Alliance – Impact of Brexit on ERNs/UK clinical networks
- Genetic Alliance AGM (Oct 19)
- CRDN Companies Forum (Nov 19) - panel speaker
- BPNA UK Annual Conference – poster and exhibition stand (Jan 20)
- Rare Disease Day Parliamentary Reception (Feb 20)

Training/mentoring:

EURORDIS Leadership School – 1-year training program completed by Allison Watson including regular active engagement with mentor Ana Mingorance (neuroscientist/patient advocate genetic epilepsies)

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 **£1,500 - £2,000** to cover unfunded committed costs for the next 6 months.

Our general reserve at 31 March 2020 was £11,074 (of which £5,500 is designated for completion of comic production/printing project), leaving £5,574 of Free Reserves which is slightly in excess of policy. The Board will review the policy in Q4 2020.

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 2020 the charity raised £24,864 through multiple income streams including Interest Received of £133 (1%):

Member Fundraising £5,778 (23%)

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|-----------------------------------|--------|
| ➤ Facebook fundraisers | £2,661 |
| ➤ Sullivan Family events | £1,994 |
| ➤ Clearview family fun day | £ 614 |
| ➤ Elliot's Prudential RIDE London | £ 423 |
| ➤ Other | £ 86 |

Member Donations £6,135 (25%)

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|-------------------------------|--------|
| ➤ Big Give Campaign (various) | £5,407 |
| ➤ Regular Donations | £ 180 |
| ➤ Ad hoc (various) | £ 366 |
| ➤ Overseas | £ 182 |

Corporate Donations £5,500 (22%)

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|----------------------------------|--------|
| ➤ Movement for Good July 2019 | £1,000 |
| ➤ Bragagnini Golf Day Sept 2019 | £1,000 |
| ➤ Tai Tarian | £ 300 |
| ➤ Big Give Campaign (pledges) | £1,150 |
| ➤ Big Give Campaign Champion HSF | £2,050 |

Online Donations £414 (2%)

- Easyfundraising, Fit4Change, AmazonSmile, Essex Lottery

Grant Funding £6,904 (28%)

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|---------------------------------|--------|
| ➤ Astor Foundation Unrestricted | £ 500 |
| ➤ GW Pharma Unrestricted | £2,000 |
| ➤ UCB Restricted | £2,500 |
| ➤ Ovid Therapeutics Restricted | £1,904 |

The charity spent £21,503 of which the main items of expenditure in support of its objectives were:

- Hosting comic workshop £5,969
- Producing comic (part 1) £3,500
- RareComms social media support £7,616
- External accounts examination £1,200

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)	 <small>Neil White (Dec 6, 2020 18:21 GMT)</small>	
Full name(s)	Neil White	Allison Jane Watson
Position (eg Secretary, Chair, etc)	Chair	Secretary
Date	5th December 2020	

Annual Trustee report 2020 FINAL

Final Audit Report

2020-12-06

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