Company no. 05460413 Charity no. 1110661

# Rare Chromosome Disorder Support Group Report and Audited Financial Statements 31 March 2019

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# For the year ended 31 March 2019

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## Reference and administrative details

# For the year ended 31 March 2019

Company number	05460413	
Charity number	1110661	
Registered office	Valiant House 3 Grange Mills Weir Road London SW12 0NE	
Operational address	The Stables Station Road West Oxted Surrey RH8 9EE	
Trustees		rectors under company law, who served during e of this report were as follows:
	Helen Campbell Sally Cohen Edna Knight, MBE Fiona de Zoete Isobel Hindle Gillian Manvell Sophie Sainty Benjamin Stern James Toop	Chair Vice Chair, Trustee (resigned October 2018) Founder, Life President, Trustee Trustee Trustee Trustee Trustee Trustee Trustee
Chief executive officer	Beverly Searle, PhD	
Company secretary	Craig Mitchell MInstF (Dip	)
Patrons	Professor Dian Donnai, U Professor Jean-Pierre Fry Professor Judith Hall, Car Baroness Pauline Neville- Professor Albert Schinzel,	ns, Belgium nada Jones, UK

## Reference and administrative details

# For the year ended 31 March 2019

Bankers	Charities Aid Foundation Kings Hill West Malling Kent ME19 4TA	Lloyds Bank PO Box 545 Faryners House 25 Monument Street London EC3R 8BQ
	United Trust Bank 1 Ropemaker Street London EC2Y 9AW	Yorkshire Building Society Yorkshire House, Yorkshire Drive Bradford BD5 8LJ
	Virgin Money plc Jubilee House Gosforth Newcastle-upon-Tyne NE3 4PL	
Auditors	Godfrey Wilson Ltd Chartered accountants and 5th Floor, Mariner House 62 Prince Street Bristol BS1 4QD	d statutory auditors

#### Report of the trustees

#### For the year ended 31 March 2019

The trustees present their report and the audited financial statements for the year ended 31 March 2019.

Reference and administrative information set out on page 1 forms part of this report. The financial statements comply with current statutory requirements, the Memorandum and Articles of Association and the Statement of Recommended Practice - Accounting and Reporting by Charities (effective from January 2015).

Welcome to our annual report and accounts for 2018-19, another incredibly busy year for Unique as demand for our frontline services saw huge increases. We welcomed and helped over 2,800 new families affected by rare chromosome and some single gene disorders, by far a record year for Unique and an increase of 87% on the previous year. For a small charity, this brings real challenges but our staff responded with customary professionalism and dedication, ensuring all those who came to us could access help and support. As our Listening Ear telephone and email helpline is the first point of contact for these families, during the year, we invested in this key service, recruiting a further part-time Information Officer, thereby increasing our capacity to respond to an ever growing number of families in need.

A significant factor in this uplift in demand is our fully mobile-responsive website. Launched in late March 2018, as it bedded-in throughout the 2018-19 year, it greatly helped new and existing families, making it easier for them to join us, get help, find and access resources and information.

A highlight of the year was bringing about a change to the law, which will benefit not just Unique and the families we support, but all UK patient support groups. In preparing for the General Data Protection Regulation (GDPR), which entered law in May 2018, we identified a risk that we could be required to delete huge amounts of valuable data, given willingly by our member families. Where organisations rely on consent as the lawful basis for processing personal data, GDPR requires a higher level of consent than previous regulations. In some instances this could have meant regularly having to attempt to obtain refreshed consent. We felt that seeking regular renewed consent from families caring for disabled children, with the huge daily challenges that entails, was unrealistic.

Unique patron Baroness Pauline Neville-Jones, working with our trustee, Sophie Sainty, Unique staff and the team at Genetic Alliance UK, managed to secure government agreement to an amendment to the law. This means that patient support groups working with certain types of historical health data which they had consent to process under the previous regulations, will not be required to refresh consents to process such data. This is a huge benefit to patient support groups in the UK, many of them small and under-resourced, working to help families affected by often rare and poorly understood conditions. In addition to Genetic Alliance UK, we worked closely with lots of smaller support groups, a great example of collaborative working for the greater good.

Financially, after a challenging year in 2017-18, this year was much more positive, ending as our best ever in terms of income. With the outlook for the charity sector and the wider economy remaining uncertain, as trustees we budgeted prudently and continued to control expenditure closely. As the need for our services continues to spiral inexorably upwards, the longer-term sustainability of Unique is our top priority. We are enormously grateful to our members and supporters for their fundraising efforts and particularly touched by those who support us whilst caring for their disabled children, with all the additional challenges that brings. We took the decision to increase our volume of applications to grant-making trusts and foundations this year and were pleased to receive grants at various levels from almost 40 different funders.

#### Report of the trustees

#### For the year ended 31 March 2019

During the coming year we intend to invest further to protect and strengthen our core services, as we are forecasting another increase in the number of families needing our help. We aim to recruit another part-time Information Officer to help families through our Listening Ear helpline, taking staffing on this service to three full-time equivalents. We are also planning three further regional family days, bringing families and professionals together and our sixth Rare Chromosome & Gene Disorder Awareness Week. In all, 2019-20 looks set to be another busy and challenging year!

Helen Campbell, Chair of Trustees, June 2019

#### Aims and objectives

At Unique, we support and inform families and individuals living with and affected by Rare Chromosome and Gene Disorders (RCDs). Present at birth, these lifelong, currently incurable conditions involve a person having parts of one or more of their chromosomes missing, added on or rearranged. Often causing severe learning and physical disabilities, many of those affected are totally reliant on their parents and carers and will remain so throughout their lives. Others are relatively mildly affected and it's only when they try to have children of their own, experiencing issues such as problems conceiving and multiple miscarriages, that they find out they have an RCD.

Our mission is to inform, support and to create networks to alleviate the isolation of anyone affected by a rare chromosome or gene disorder and to raise public awareness. We aim to:

- provide information and support to anyone affected by and dealing with RCDs;
- relieve the isolation of those affected and their families;
- promote and participate in research; and
- act as an umbrella organisation for all RCDs.

As diagnostic technology has advanced, many more people are receiving a diagnosis of an RCD. However, despite collectively affecting as many as 1 in 200 live born babies, the rarity of individual disorders means there remains a lack of knowledge and understanding about them among many doctors and other health professionals. Having received a complex diagnosis for their child, parents will inevitably have lots of questions but many go unanswered, adding to their distress and feeling of desperate isolation. This is where Unique comes in.

#### Activities and achievements

Our activities can be summarised under three distinct strands:

- supporting families;
- providing specialist information; and
- networking to raise awareness.

#### Supporting families

Unique supports parents and carers of those with RCDs, helping them understand their child's diagnosis and begin to come to terms with it. Given the often complex medical and genomic terminology involved, parents need to have it explained in an accessible, understandable way. Our team are able to do this and outline what the future might hold for their child, the health and other issues they are likely to face and the sort of care, therapies and other help they might need.

Key to the support we provide is **the** *Unique* Listening Ear telephone and email help service. When parents need help, it's the first point of contact. Our experienced staff are able to answer many of their questions but also empathise and where possible provide some renewed hope. Medical and other professionals also contact us for help when counselling patients and planning care.

#### Report of the trustees

#### For the year ended 31 March 2019

As well as our Listening Ear, we are able to help families via our **Family matching service**, linking those living with similar conditions or facing similar challenges. We run **Family Events**, e.g. regional family days bringing local families together to meet others and develop mutual support networks. Expert professionals including clinical and laboratory-based geneticists also attend, furthering our knowledge of RCDs and helping families access help, information and other resources.

## Achievements during 2018-19: Supporting families

During 2018-19, we saw an incredible increase in demand for our help and support. 2,802 new families joined us, a record year by far and a huge increase of 87% on the previous year. This took our total membership to 19,340 families, representing over 21,000 individuals affected by RCDs.

Staff working on our Listening Ear service answered 10,409 emails and 407 calls from families plus a further 1,420 enquiries from medical and other professionals. They also responded to a growing number of queries from families received via social media, including 700 messages via our public Facebook page received from families in need of help. To meet their needs, our staff have adapted the way they work as families' contact preferences change.

We ran a further family day, for families in South London and Surrey, attended by approximately 150 parents, carers and children (including siblings of those affected). We were delighted to be joined by geneticists from Guy's Hospital in London and Healthcare Scientists from Great Ormond Street Hospital. With children's entertainment and lunch provided for all, families were able to meet others in the same boat and learn more about genetics in a relaxed and fun environment.

Our Family Support Officer reached out to all new families with resources and information and we linked many hundreds of families with other new and existing Unique members to enable them to get to know others, swap tips and form mutual support networks. This helps families realise they are not alone on their journey.

## Providing specialist information

Through the **Unique Information Project**, we produce family-friendly, accessible information guides, to specific RCDs. Independently medically-verified by experts in the field, volunteering their time, the guides contain a mixture of data provided by Unique member families keen to help others and information gleaned via painstaking research into the often limited published medical literature. Available free of charge in digital or paper format, they cover medical and health issues related to a specific RCD, but also other relevant topics such as effects on learning and behaviour.

Alongside our information guides, we publish '**practical guides**' for families on general but highly relevant topics such as sleep issues, toileting, dental problems, days out and even travel insurance.

The **Unique** database/patient registry, containing rich data provided by member families, forms the bedrock of the information we provide. As well as purely medical data, it includes behavioural, social, educational and developmental information and is used anonymously to inform researchers, geneticists and other professionals and by our staff to guide families on their child's condition.

## Achievements during 2018-19: Providing specialist information

Our two part-time Information Officers published 13 brand new information guides to specific rare chromosome and single gene disorders, taking our total beyond 250. A further 6 of our existing guides were substantially updated or revised as member families provided lots more information and we continued to keep abreast of the latest published medical research.

#### Report of the trustees

#### For the year ended 31 March 2019

We completed a major project with a group of families, resulting in two 60-page guides to 'duplications of 9p'.

33 more guides were translated by volunteers for those for whom English is not their first language and we began a project with Chinese volunteers to translate 31 guides – a first for us. We now have guides in 12 languages, including Arabic, French, German, Spanish and Russian.

We will always work collaboratively with other support groups whenever possible and this year we worked with groups including the Norrie Disease Foundation and Wolf-Hirschhorn Syndrome to produce new, world first resources for families.

Having had a child with an RCD, lots of families ask us 'can it happen again?' so we have updated this section in all our microdeletions and microduplications information guides with new guidance to help answer them.

Several new 'practical guides' were published, including a guide to the issues around Puberty and also to obtaining Travel Insurance, diverse topics but reflecting pressing needs of families.

Brand new 'quick read' guides, to Single Gene Disorders and X-inactivation have been written by our team, reviewed by families and are under review by professionals, prior to wider publication.

Our Information Officer Dr. Claire Andersen ran a workship on producing patient information guides at the Genetic Alliance UK annual conference in September 2018.

We continued updating all data held in our patient registry/database. It forms the basis of our published information and is used daily to help members and professionals. A huge project converting all historical paper records to digital was completed, part of our digital strategy.

#### Networking to raise awareness

Despite rapid advances in technology, the individual rarity of the chromosome and single gene disorders we cover means awareness and understanding generally remain low. Networking and awareness-raising are therefore key to improving the care of those affected.

We have strong relationships with professionals, including clinical and laboratory-based geneticists across the UK and beyond, as well as a huge number of other clinicians, therapists, charities and other organisations. Hundreds of expert professionals volunteer their time to help us, e.g. by independently verifying our information guides prior to publication. Our staff regularly give presentations to a diverse range of audiences, including professionals, policy makers, funders and family members and sit on advisory boards and policy boards, from national down to local level. We have a network of over 200 local volunteer contacts, many of them parents, who help families in their area, signposting them to local services and resources.

A significant strand of our 5-year operating plan is our digital strategy, which is key to raising awareness of Unique and RCDs. Key to this is our very active **Social Networks** which have two strands: promoting the charity and supporting families in safe, supportive, moderated environments. Our fully mobile-responsive website has lots of free information and other resources and includes an online form, via which the majority of new families join us.

#### Report of the trustees

#### For the year ended 31 March 2019

## Achievements during 2018-19: Networking to raise awareness

Our CEO, Dr. Beverly Searle, continued to participate in the DHSC UK Rare Diseases Policy Board as one of two patient representatives.

Our Information Officer, Dr. Sarah Wynn, continued to sit on the advisory board for the British Society for Genomic Medicine's (BSGM) Policy & Ethics Committee.

Dr. Searle gave the keynote speech "Patient care – far more than just a test result! Why what you do matters" to the 2018 intake of 300+ young scientists at National School of Healthcare Science's Scientist Training Programme in Birmingham. She also presented to NCARDS (National Congenital Anomalies and Rare Disease Register) staff about the challenges our member families face, not least the uncertainty of outcomes.

Our Information Officer, Arti Patel, spoke to a large audience at the Festival of Genomics about Unique and what we do to support families and professionals.

Dr. Searle participated in the "Shaping the Future of Rare Disease Together" summit for global patient advocacy leaders at the invitation of the Ilumina Foundation.

Our Chief Operating Officer, Craig Mitchell, gave presentations to companies who are supporting the charity's work, explaining who we help and the services we provide.

We had awareness-raising stands at conferences including BSGM and the Clinical Genetics Society, helping to spread the word about Unique's work to a wider, professional audience.

During the year we passed 28,000 followers on our public Facebook page and 6,000 Twitter followers. We also have more than 1,500 followers to our Instagram. Trustees took the decision to appoint the charity's first part-time Social Media Officer, who drives our digital marketing, including awareness-raising, disseminating information and fundraising. Many families now find Unique and therefore the support they need, via social media.

June saw the fifth Chromosome and Gene Disorder Awareness Week which was again very successful, the highlight being a video made by actor Josh Gad, viewed more than 200,000 times during the week. We raised £10,000 through Facebook alone and lots of people held cake sales, sold merchandise, took part in other fundraising such as skydives, gave presentations or just handed out leaflets. Our own Facebook page had a reach of almost 300,000 during the week.

#### Public benefit

The trustees confirm their due regard for the Charity Commission Guidance on Public Benefit in reviewing Unique's aims, objectives and activities undertaken, planning future strategy and setting policy. As the UK's only charity working in the specific field of RCDs, throughout this report we detail the ways in which we help beneficiaries, providing specialist information as well as softer support.

For the wider public benefit, Unique has actively supported the development and roll-out of the new Genomic Medicine Service, building on the NHS contribution to the 100,000 Genomes Project, to provide families with a diagnosis of a rare disease. During the year, Dr. Searle also participated in the DHSC's Rare Disease Policy Board as a patient representative. The genomics and rare disease expertise gained from these initiatives will benefit more mainstream areas of medicine, e.g. cardiology and respiratory medicine, deliver personalised medicine and stimulate research.

#### Report of the trustees

#### For the year ended 31 March 2019

#### Infrastructure

Trustees and staff continued to ensure Unique's infrastructure is fit for purpose. Data security is paramount, with sensitive medical information only accessed and processed by staff on a hierarchical basis. All data are processed in accordance with the General Data Protection Regulation (GDPR).

## Volunteers

We are very grateful to the large number of volunteers who helped during the year, including:

- over 200 local volunteer contacts, supporting member families in their area;
- over 30 geneticists and other professionals verifying our information guides prior to publication;
- healthcare scientists and clinical geneticists attending our events;
- volunteers translating our information guides into a variety of different languages;
- a number of others assisting in areas such as marketing and promotional activities; and
- hundreds of our members and supporters undertaking voluntary fundraising.

#### Financial review 2018-19

#### Income

Our total income for the year is £391,798, representing our best ever year in terms of total income (2017-18: £288,592). Unrestricted income from donations and fundraising from members and supporters, corporate, trusts and foundations totalled £330,282. This is a relatively high proportion of our total income but it means funds can be directed to where they are most needed and we are not reliant on restricted funds for specific projects, which can be for a relatively short, fixed-term. From charitable trusts and foundations, we received unrestricted funding of £26,000 and restricted income of £60,886. This was to cover costs associated with family support in various regions across the UK, regional events for families and published information guides.

## Expenditure

Total expenditure for the year was £281,633, lower than the previous year (2017-18: £315,855) as we continued to budget cautiously and prudently against a backdrop of an uncertain economic outlook, particularly for small charities. Trustees and senior staff met regularly during the year (in person and via conference call), monitoring financial performance to take action as necessary. Sound and robust financial management procedures enable us to continue to invest in staff, resources and infrastructure to ensure we can meet the needs of our beneficiaries over the longer-term, particularly as demand for our services continues its explosive increase.

#### Level of reserves

The Trustees have decided to adopt a policy, reviewed annually, of holding a minimum reserve equivalent to four months' average operating costs for the previous year. For this year, this equates to not less than £94000. Having ensured expenditure remained tightly under control, reserves at the end of the year are at £389,925, of which unrestricted reserves stand at £375,589. Reserves protect our current and future beneficiaries, safeguarding key services to ensure the charity's future sustainability and reflect planned expenditure over the coming year. Trustees have also decided to designate £40,000 to protect the Listening Ear Telephone and Email helpline service, a key part of our service to families.

#### Report of the trustees

#### For the year ended 31 March 2019

#### Update: Unique's 5-Year Strategic Plan

Our 5-year strategy, covering 2017-22 and available on our website at www.rarechromo.org underpins our activities. To better serve our beneficiaries, a digital upgrade is a key strand of this. Our new, fully mobile-responsive website has helped expand our reach and partly driven a huge uplift in the numbers of new members. We continued to make progress with expanding our information resources, reached a wider audience via our awareness week and brought families together through our family matching service, at our latest family day and virtually via our secret/closed social media groups.

Staff and trustees remain fully aware of our statutory responsibilities in the area of fundraising and we are now registered with the Fundraising Regulator. We will continue our diverse fundraising efforts to avoid over-reliance on one particular income stream. By minimising risk, trustees seek to ensure the charity's long-term sustainability.

#### Structure, governance and management

The trustees delegate day-to-day management of the charity's activities to Dr. Beverly Searle, Chief Executive Officer (CEO). Unique currently employs ten staff, including the CEO, three of whom are full-time, with the other seven staff working part-time. Craig Mitchell (COO) is also Company Secretary.

## Corporate and social responsibility and sustainability

Our policy is to seek all members of our communities who may be affected by a RCD irrespective of race, religion, sexuality, marital status or culture. We are an equal opportunity employer.

During the year, four of our part-time staff worked exclusively from home but regularly visited the office as well as communicating via VOIP to minimise costs and our carbon footprint.

#### Management of risk

Unique's risk register, containing the major risks (identified by trustees and senior staff) to which the charity could be exposed, is regularly reviewed and updated. A disaster recovery plan is in place, with appropriate contingency plans as operating conditions and/or performance change. The trustees meet four times per year, with senior staff present, with the charity's position kept under review at each meeting and at other times as necessary.

#### Compliance and training

Given the importance to our work of personal and sensitive medical data, staff and trustees are aware of the requirements of data protection law and have received training in this area. Our COO has attended workshops provided by organisations such as the Charity Finance Group and ACAS to ensure regulatory compliance. Trustees took the decision that all staff will undergo a DBS check and safeguarding training and this is ongoing. We engaged Carecheck to carry out DBS checks.

Unique has an Internal Research and Ethics Committee (comprising the CEO, the Senior Information Officer, a Medical Advisor, a trustee and an adult clinician sibling of a member with a RCD) to appraise research proposals of professionals requesting Unique's approval.

Staff undergo regular performance appraisals to monitor performance, with reference to Unique's charitable aims. Training needs are identified and training sourced where appropriate.

#### Report of the trustees

#### For the year ended 31 March 2019

#### Governance

Unique is an incorporated charity and company limited by guarantee, governed by a Memorandum and Articles of Association. Governance and management structures of the charity are kept under constant review to ensure optimal use of resources. Trustees correspond regularly via email and Skype, particularly to keep financial performance under review. By doing so, we take a proactive approach to any fluctuations in income and are able to refine our strategy accordingly.

The charity currently has eight trustees with diverse backgrounds including law, business, marketing, finance, accounting, IT, the charity sector and education. During the year Sally Cohen resigned as Trustee-Director after more than 8 years' service, for which we are hugely grateful. New trustees are recruited by advertising as widely as possible, through our own networks and more widely and we operate an equal opportunity policy for recruitment of trustees and staff.

Registered members of the company limited by guarantee and others with an interest in Unique were invited to attend the Annual General Meeting which was held in November 2018 in central London and are kept informed by the Company Secretary.

#### Statement of responsibilities of the trustees

The trustees (who are also directors of the charity for the purposes of company law) are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and of the income and expenditure of the charity for that period. In preparing those financial statements the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and accounting estimates that are reasonable and prudent;
- state whether applicable UK accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which enable them to ensure that the financial statements comply with the Companies Act 2006. The trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditors are unaware; and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

#### Report of the trustees

#### For the year ended 31 March 2019

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Members of the charity guarantee to contribute an amount not exceeding £10 to the assets of the charity in the event of winding up. The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

#### Auditors

Godfrey Wilson Limited were re-appointed as auditors to the charitable company during the year and have expressed their willingness to continue in that capacity.

Approved by the trustees on 11 October 2019 and signed on their behalf by

E Micnight

Edna Knight - Trustee (Life President)

Ullen Campbell

Helen Campbell - Trustee (Chairman)

#### Independent auditors' report

## To the members of

#### Rare Chromosome Disorder Support Group

## Opinion

We have audited the financial statements of Rare Chromosome Disorder Support Group (the 'charity') for the year ended 31 March 2019 which comprise the statement of financial activities, balance sheet and the related notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 March 2019 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

#### **Basis for opinion**

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

#### Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charity's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

#### Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

#### Independent auditors' report

#### To the members of

#### Rare Chromosome Disorder Support Group

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

## Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the trustees' report (incorporating the directors' report) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the trustees' report (incorporating the directors' report) has been prepared in accordance with applicable legal requirements.

#### Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' report. We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us;
- the financial statements are not in agreement with the accounting records and returns;
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not obtained all the information and explanations necessary for the purposes of our audit.

#### Responsibilities of the trustees

As explained more fully in the trustees' responsibilities statement set out in the trustees' report, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as they determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

#### Independent auditors' report

#### To the members of

#### Rare Chromosome Disorder Support Group

#### Our responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

#### Use of our report

This report is made solely to the charity's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charity's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity's members as a body, for our audit work, for this report, or for the opinions we have formed.

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Date: 24 OCTOBER 2019

Alison Godfrey FCA (Senior Statutory Auditor)

For and on behalf of: **GODFREY WILSON LIMITED** Chartered accountants and statutory auditors 5th Floor Mariner House 62 Prince Street Bristol BS1 4QD

Statement of financial activities (incorporating an income and expenditure account)

## For the year ended 31 March 2019

	Note	Restricted £	Unrestricted £	2019 Total £	2018 Total £
Income from:	0	040	202 500	204 400	0.40,000
Donations and legacies Charitable activities:	3	810	323,599	324,409	246,020
Family support services	4	31,027	-	31,027	20,329
Information and awareness	5	29,859	4,749	34,608	20,502
Investments		-	1,934	1,934	1,741
Total income		61,696	330,282	391,978	288,592
Expenditure on: Raising funds Charitable activities: Family support services Information and awareness		- 22,637 31,153	41,894 117,630 <u>68,319</u>	41,894 140,267 99,472	55,683 136,369 123,803
Total expenditure	6&7	53,790	227,843	281,633	315,855
Net income / (expenditure) and net movement in funds	8	7,906	102,439	110,345	(27,263)
Reconciliation of funds Total funds brought forward		6,430	273,150	279,580	306,843
Total funds carried forward		14,336	375,589	389,925	279,580

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in note 17 to the accounts.

## **Balance sheet**

#### As at 31 March 2019

	Note	£	2019 £	2018 £
Fixed assets Tangible fixed assets Investments	11 12		3,284 700	3,541 700
			3,984	4,241
<b>Current assets</b> Stock Debtors Cash at bank and in hand	13 14	1,147 16,673 <u>380,244</u> 398,064		1,567 12,957 272,703 287,227
Creditors: amounts due within 1 year	15	12,123		11,888
Net current assets			385,941	275,339
Net assets	16		389,925	279,580
Funds Restricted income funds Unrestricted funds: Designated funds General funds	17		14,336 40,000 335,589	6,430 40,000 233,150
Total charity funds			389,925	279,580

Approved by the trustees on 11 October 2019 and signed on their behalf by

E. M Kniget

Edna Knight - Trustee (Life President)

Hulen Campbell - Trustee (Chair)

#### Notes to the financial statements

#### For the year ended 31 March 2019

#### 1. Accounting policies

#### a) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities in preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Rare Chromosome Disorder Support Group meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

#### b) Going concern basis of accounting

The accounts have been prepared on the assumption that the charity is able to continue as a going concern, which the trustees consider appropriate having regard to the current level of unrestricted reserves. There are no material uncertainties about the charity's ability to continue as a going concern.

#### c) Income

Income is recognised when the charity has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income from grants, whether 'capital' or 'revenue', is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably.

For legacies, entitlement is taken as the earlier of: the date on which the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the exector(s) that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

Income received in advance of provision of an event or contract for services is deferred until criteria for income recognition are met.

#### d) Donated services and facilities

Donated professional services and donated facilities are recognised as income when the charity has control over the item, any conditions associated with the donated item have been met, the receipt of economic benefit from the use by the charity of the item, is probable and the economic benefit can be measured reliably. In accordance with the Charities SORP (FRS 102), general volunteer time is not recognised.

On receipt, donated professional services and donated facilities are recognised on the basis of the value of the gift to the charity which is the amount the charity would have been willing to pay to obtain services or facilities of equivalent economic benefit on the open market; a corresponding amount is then recognised in expenditure in the period of receipt.

#### Notes to the financial statements

#### For the year ended 31 March 2019

#### e) Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity: this is normally upon notification of the interest paid or payable by the bank.

#### f) Funds accounting

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charity's work or for specific projects being undertaken by the charity.

#### g) Expenditure and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

#### h) Allocation of support costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. These costs have been allocated between activities on the following basis, which is an estimate of staff time spent on each activity:

	2019	2018
Raising funds	9.0%	14.0%
Family support services	43.0%	30.5%
Information and awareness	48.0%	55.5%

#### i) Tangible fixed assets

Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life. The depreciation rates in use are as follows:

Computer equipment 4 years straight line

Items of equipment are capitalised where the purchase price exceeds £500.

#### j) Fixed asset investments

Investments are stated at market value. The statement of financial activities includes any recognised gains or losses on revaluations and disposals during the year.

#### k) Stock

Stock is included at the lower of cost or net realisable value.

#### I) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

#### Notes to the financial statements

#### For the year ended 31 March 2019

## m) Cash at bank and in hand

Cash at bank and cash in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

#### n) Creditors

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

#### o) Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value.

#### p) Foreign currency

Transactions in foreign currencies are translated at rates prevailing at the date of the transaction. Balances denominated in foreign currencies are translated at the rate of exchange prevailing at the year end.

#### q) Pension costs

The company operates a defined contribution pension scheme for its employees. There are no further liabilities other than that already recognised in the SOFA.

#### r) Operating leases

Rentals applicable to operating leases where substantially all of the benefits and risks of ownership remain with the lessor are charged against profits on a straight-line basis over the period of the lease.

#### s) Accounting estimates and key judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying values of assets and liabilities that are not readily apparent from other sources. The estimates and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision affects only that period, or in the period of the revision and future periods if the revision affects both current and future periods.

The key sources of estimation uncertainty that have a significant effect on the amounts recognised in the financial statements are described below.

#### Depreciation

Depreciation is provided at rates calculated to write down the cost of each asset to its estimated residual value over its expected useful life. The depreciation rates in use are as follows:

Computer equipment

4 years straight line

## Notes to the financial statements

## For the year ended 31 March 2019

# 2. Prior period comparatives

. Phot period comparatives			2018
	Restricted £	Unrestricted £	Total £
Income from:			
Donations and legacies	2,058	243,962	246,020
Charitable activities			
Family support services	20,329	-	20,329
Information and awareness	14,850	5,652	20,502
Investments	-	1,741	1,741
Total income	37,237	251,355	288,592
Expenditure on:			
Raising funds	-	55,683	55,683
Charitable activities			
Family support services	25,861	110,508	136,369
Information and awareness	15,971	107,832	123,803
Total expenditure	41,832	274,023	315,855
Net expenditure and net movement in funds	(4,595)	(22,668)	(27,263)

# 3. Donations and legacies

	Restricted £	Unrestricted £	2019 Total £
Grants more than £5,000:			
D & J Hunter Charitable Trust	-	10,000	10,000
Grants £5,000 or less	-	16,000	16,000
General donations	650	48,645	49,295
Corporate donations	-	33,917	33,917
Overseas donations	-	27,399	27,399
Gift aid	-	22,863	22,863
Give As You Earn (GAYE)	-	1,121	1,121
Pyramids	-	435	435
Donations from fundraising activities	160	163,219	163,379
	810	323,599	324,409

## Notes to the financial statements

#### For the year ended 31 March 2019

3. Donations and legacies (continued) Prior year comparative

Prior year comparative			2018
	Restricted	Unrestricted	Total
	£	£	£
Grants more than £5,000:			
D & J Hunter Charitable Trust	-	15,000	15,000
Grants £5,000 or less	-	4,000	4,000
Donated goods / services *	-	12,921	12,921
General donations	562	42,590	43,152
Corporate donations	-	18,999	18,999
Overseas donations	-	11,084	11,084
Gift aid	-	19,539	19,539
Give As You Earn (GAYE)	-	1,254	1,254
Pyramids	-	431	431
Legacy	-	4,230	4,230
Donations from fundraising activities	1,496	113,914	115,410
	2,058	243,962	246,020

\* Donated services consists of Google AdWords (free web advertising)

## 4. Charitable activities: family support services

L	£	Total £
31,027		31,027
31,027		31,027
Restricted £	Unrestricted £	2018 Total £
9,229 <u>11,100</u> 20,329		9,229 11,100 20,329
	31,027 Restricted £ 9,229	<u>31,027</u> - <u>31,027</u> - <u>31,027</u> - Restricted Unrestricted £ £ 9,229 - 11,100 -

## Notes to the financial statements

## For the year ended 31 March 2019

#### 5. Charitable activities: information and awareness

	Restricted £	Unrestricted £	2019 Total £
Grants < £5,000 Christmas card and merchandise sales	29,859 	4,749	29,859 4,749
	29,859	4,749	34,608
Prior year comparative	Restricted £	Unrestricted £	2018 Total £
Grants < £5,000 Christmas card and merchandise sales	14,850 	- 5,652	14,850 5,652
	14,850	5,652	20,502

## Notes to the financial statements

## For the year ended 31 March 2019

## 6. Total expenditure

	Raising funds £	Family support £	Information and awareness £	Support and governance £	2019 Total £
Audit and accountancy	-	-	-	3,600	3,600
Computer expenses	496	3,098	2,518	-	6,112
Depreciation	355	1,696	1,894	-	3,945
Event costs	-	4,263	-	-	4,263
Insurance	-	-	-	2,185	2,185
Office costs & rent	1,708	9,532	9,315	416	20,971
Postage and distribution	402	10,348	2,138	24	12,912
Printing and design	15	5,520	3,693	-	9,228
Staff costs (note 9)	26,381	91,779	58,279	19,634	196,073
Stationery	91	585	531	-	1,207
Subscriptions, licences and charges	10,058	44	3,809	666	14,577
Training and other staff costs	-	-	3,000	112	3,112
Travel and subsistence	-	1,409	973	211	2,593
Website and database development		375	480	<u> </u>	855
Sub-total	39,506	128,649	86,630	26,848	281,633
Allocation of support and governance costs	2,388	11,618	12,842	(26,848)	-
Total expenditure	41,894	140,267	99,472	<u> </u>	281,633

Governance costs were £6,145 (2018: £5,677).

## Notes to the financial statements

## For the year ended 31 March 2019

## 7. Total expenditure (continued) Prior year comparative

Phor year comparative			Information and	Support and	
	Raising funds	Family support	awareness	governance	2018 Total
	£	£	£	£	£
	-	~	~		
Advertising	-	-	227	12,922	13,149
Audit and accountancy	-	-	-	3,480	3,480
Computer expenses	4,851	1,282	2,341	-	8,474
Depreciation	424	957	1,757	-	3,138
Insurance	-	-	-	2,027	2,027
Office costs	412	2,129	2,009	260	4,810
Office rent	2,505	5,750	10,295	-	18,550
Postage and distribution	648	12,289	2,560	43	15,540
Printing and design	-	7,099	2,947	-	10,046
Room hire and event costs	45	6,763	55	-	6,863
Staff costs	30,049	86,018	62,525	19,255	197,847
Stationery	264	883	1,150	12	2,309
Subscriptions, licences and charges	11,029	55	2,991	402	14,477
Training and other staff costs	8	420	3,128	20	3,576
Travel and subsistence	55	759	356	103	1,273
Website and database development		216	10,080		10,296
Sub-total	50,290	124,620	102,421	38,524	315,855
Allocation of support and governance costs	5,393	11,749	21,382	(38,524)	
Total expenditure	55,683	136,369	123,803		315,855

## Notes to the financial statements

#### For the year ended 31 March 2019

- 8. Net movement in funds
  - This is stated after charging:

	2019 £	2018 £
Depreciation	3,945	3,138
Trustees' remuneration	Nil	Nil
Trustees' reimbursed expenses	Nil	Nil
Auditors' remuneration:		
<ul> <li>Statutory audit (including VAT)</li> </ul>	3,600	3,480

## 9. Staff costs and numbers

Staff costs were as follows:	2019 £	2018 £
Salaries and wages Social security costs Pension contributions	177,459 11,896 6,718	178,312 12,720 6,815
	196,073	197,847

No employee earned more than £60,000 during the year (2018: none).

The key management personnel of the charity comprise the trustees, the Chief Executive and the Chief Operating Officer. The total employee benefits comprising gross wages, employer pension contributions and employer NI contributions received by the charity's key management personnel in the period was £90,437 (2018: £90,526).

	2019 No.	2018 No.
Average staff head count	9.00	9.00
Average full time equivalent	6.00	6.00

## 10. Taxation

The charity is exempt from corporation tax as all its income is charitable and is applied for charitable purposes.

## Notes to the financial statements

## For the year ended 31 March 2019

#### 11. Tangible fixed assets

	Computer Equipment
•	£
Cost	
At 1 April 2018	22,228
Additions in year	3,841
Disposals	(9,805)
At 31 March 2019	16,264
Depreciation	
At 1 April 2018	18,687
Charge for the year	3,945
On disposal	(9,652)
At 31 March 2019	12,980
Net book value	
At 31 March 2019	3,284
At 31 March 2018	3,541
12. Investments	
	Artwork £
At 31 March 2019	700
At 31 March 2018	700

A Tracey Emin print was donated in 2005. The trustees have no immediate plans to sell the print consequently it has been reported as a fixed asset investment in the accounts. It is valued at the average of two professional valuations which were provided in May 2012. No revaluations were carried out in the year. The trustees are satisifed that the print is carried at an appropriate value at 31 March 2019.

## 13. Stock

	2019 ج	2018 ج
Merchandise	1,147	۲ 1,567

## Notes to the financial statements

## For the year ended 31 March 2019

## 14. Debtors

	2019 £	2018 £
Trade debtors	200	128
Prepayments	7,651	7,782
Accrued income	8,822	5,047
	16,673	12,957
15. Creditors : amounts due within 1 year	2019 £	2018 £
Trade creditors	510	-
Accruals	6,916	7,459
Other taxation and social security	3,973	3,770
Pension creditor	724	659
	12,123	11,888

# 16. Analysis of net assets between funds

-	Restricted funds £	Designated funds £	General funds £	Total funds £
Tangible fixed assets	-	-	3,284	3,284
Investments	-	-	700	700
Net current assets	14,336	40,000	331,605	385,941
Net assets at 31 March 2019	14,336	40,000	335,589	389,925

# Prior year comparative

	Restricted funds £	Designated funds £	General funds £	Total funds £
Tangible fixed assets Investments Net current assets	- - 6,430	- - 40,000	3,541 700 228,909	3,541 700 275,339
Net assets at 31 March 2018	6,430	40,000	233,150	279,580

#### Notes to the financial statements

#### For the year ended 31 March 2019

#### 17. Movements in funds

	At 1 April			At 31 March
	2018 £	Income £	Expenditure £	2019 £
Restricted funds	L	L	L	Z
Family support services	4,430	31,837	(22,637)	13,630
Information and awareness	2,000	29,859	(31,153)	706
Total restricted funds	6,430	61,696	(53,790)	14,336
Unrestricted funds Designated funds:				
Listening Ear Fund	40,000			40,000
Total designated funds	40,000		-	40,000
General funds	233,150	330,282	(227,843)	335,589
Total unrestricted funds	273,150	330,282	(227,843)	375,589
Total funds	279,580	391,978	(281,633)	389,925

## Purposes of restricted funds

#### Family support services

This is funding for our frontline services to families such as our Listening Ear telephone and email helpline and Regional Family Days. It includes grants received during the year from a number of funders, such as the Jeans 4 Genes and Mary Homfray Charitable Trust, plus various other trusts and foundations, kindly helping us to support families in regions across the UK as part of our wider service.

#### Information and awareness

Funds received include grants from The Clara Burgess Charitable Trust to enable us to continue to increase our library of 'practical' information guides for families, and The Hamamelis Trust, towards information guides to specific rare chromosome disorders, as well as from various other regional trusts and foundations, supporting our work to provide families with specialist information as part of our wider service.

#### Purposes of designated funds

#### Listening Ear Fund

The trustees designated £40,000 from general funds to the charity's 'Listening Ear' project in 2012. This sum was to ensure that the Unique helpline, a frontline service providing expert response to first-time callers from the UK and around the world, would be staffed appropriately for at least part of each UK working day during each year. The fund will be spent if and when general funds are unavailable to cover the cost of running the service.

## Notes to the financial statements

#### For the year ended 31 March 2019

Prior period comparative				
	At 1 April			At 31 March
	2017	Income	Expenditure	2018
	£	£	£	£
Restricted funds				
Family support services	9,650	20,641	(25,861)	4,430
Information and awareness	1,375	16,596	(15,971)	2,000
Total restricted funds	11,025	37,237	(41,832)	6,430
Unrestricted funds				
Designated funds:				
Listening Ear Fund	40,000		-	40,000
Total designated funds	40,000	-	-	40,000
General funds	255,818	251,355	(274,023)	233,150
Total unrestricted funds	295,818	251,355	(274,023)	273,150
Total funds	206 942	200 502	(215 955)	270 590
i otai iulius	306,843	288,592	(315,855)	279,580

## 18. Operating leases

The charity had operating leases for land and buildings at the year end with total future minimum lease payments as follows:

	2019	2018
	£	£
Amount falling due:		
Within 1 year	7,500	18,600
Within 2 - 5 years	<u> </u>	7,750

## 19. Related party transactions

There were no related party transactions during the year ended 31 March 2019, or the prior year.

#### 20. Financial instruments

	2019	2018
	£	£
<b>-</b>		700
Financial assets measured at fair value	700	700
Financial assets measured at amortised cost	369,707	279,445
Financial liabilities measured at amortised cost	(8,150)	(8,118)

Financial assets measured at fair value comprise investment assets. Financial assets measured at amortised cost comprise cash and cash equivalents, trade debtors, accrued income and other debtors. Financial liabilities measured at amortised cost comprise trade creditors, accruals, and other creditors.