

Company no. 05460413
Charity no. 1110661

**Rare Chromosome Disorder Support
Group**

Report and Audited Financial Statements

31 March 2020

Rare Chromosome Disorder Support Group

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Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2020

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	Trustees, who are also directors under company law, who served during the year and up to the date of this report were as follows: Helen Campbell Chair Edna Knight, MBE Founder, Life President, Trustee Fiona de Zoete Trustee Isobel Hindle Trustee Gillian Manvell Trustee Shwetha Ramachandrappa Trustee (appointed 11 November 2019) Sophie Sainty Trustee Benjamin Stern Trustee James Toop Trustee
Chief executive officer	Beverly Searle, PhD
Company secretary	Craig Mitchell MInstF (Dip)
Patrons	Professor Dian Donnai, UK Professor Jean-Pierre Fryns, Belgium Professor Judith Hall, Canada Baroness Pauline Neville-Jones, UK Professor Albert Schinzel, Switzerland

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Reference and administrative details

For the year ended 31 March 2020

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 statutory auditors
5th Floor, Mariner House
62 Prince Street
Bristol
BS1 4QD

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2020

The trustees present their report and the audited financial statements for the year ended 31 March 2020.

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 2019).

On behalf of the trustees, a warm welcome to Unique's annual report and accounts for the year ended 31 March 2020. As we ended the year, the Covid-19 pandemic was unfolding with the UK going into 'lockdown' and as we present this report we enter a second period of increasing uncertainty and local lockdowns. In times where large sectors of the population, both locally and globally, are experiencing isolation and accessibility to services has been reduced, the role and social purpose of Unique comes into strong focus. The pandemic has brought unprecedented challenges for all charities, both operationally and financially. At Unique we hope and believe that we have budgeted cautiously and prudently and that we are in a relatively strong position to weather the coming storm. Operationally, we have prioritised the health and safety of the team and worked to mitigate the impact of Covid-19 on the continuing deliverance of services to members. I, and the rest of the board of trustees, thank all our staff for their ongoing commitment.

Before the pandemic hit, Unique had a very positive year and our activities and achievements are detailed in this report. Our membership continued to grow and our team welcomed and helped over 2,700 new families struggling to understand their child's diagnosis of a rare chromosome or gene disorder. They were on hand to answer their many questions, provide tailored information and match them with other families with children who have similar symptoms or challenges.

Our membership growth represented a more than 50% increase on the average number for the previous five years. As a result we took the decision to further increase the capacity of our frontline service, recruiting another part-time Information Officer. We also strengthened the board and were delighted to welcome Dr. Shwetha Ramachandrappa, a Consultant Clinical Geneticist as a trustee. Shwetha brings a new and vital perspective to inform Unique's governance.

2018-19 had been our best ever year for income. In 2019-20 we saw a more typical level of income with a slight but planned deficit. This reflects decisions taken to increase our capacity to help those who need us. We ended the year in a relatively healthy financial position, which has helped us through the rest of 2020 when revenue has dropped further. We continue our prudent, careful approach to budgeting and expenditure to ensure sustainability over the longer-term.

As always, we have been truly humbled and grateful for the support of huge numbers of supporters, many of them families who go the extra mile to raise funds whilst at the same time caring for their disabled children. We are also grateful to the trusts and foundations who made grants and to corporates, particularly Sackers LLP who supported us through the year.

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For the year ended 31 March 2020

During the year to March 2020, the new NHS Genomic Medicine service was beginning to be rolled out which indicated that we would have even greater numbers of families coming to us after receiving a diagnosis. In March, the Covid-19 pandemic and lockdown changed this, at least temporarily, with geneticists/genetic counsellors redeployed and genetics laboratories re-focused to help fight the virus. 'Routine' chromosome and gene disorder testing have been put on hold. This meant that during March we were inundated with questions from anxious parents about Covid-19 and whether their family members with chromosome and gene disorders are more susceptible to it. Many have received a diagnosis for their child from clinicians not trained in depth in genetics and genomics, leaving them with many unanswered questions that in many cases often only Unique can answer. This unprecedented challenge looks set to continue well into 2020-21 and we will monitor this developing situation on an ongoing basis to refine the charity's response as it develops through the coming months.

Thank you for reading this report and for your interest in Unique and our work. Please do contact us if you have any questions or would like to support us.

Helen Campbell, Chair of trustees

Aims and objectives

Unique's mission is to inform, support and network to alleviate the isolation of anyone affected by a rare chromosome or autosomal dominant gene disorder (RCD) and to raise public awareness. These are complex, naturally-occurring conditions, present at birth but often not inherited from a parent. Life-limiting, sometimes life-threatening and causing often severe medical issues, learning and physical disabilities, there is currently no cure. They involve parts of one or more of a person's chromosomes being missing, added on or rearranged. Many of those affected are totally reliant on their parents and carers throughout their lives. Others are affected relatively mildly, diagnosed only when they try to have children and face issues like problems conceiving and multiple miscarriages.

To help those affected and their families, our aims are 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.

Rapidly developing technology means many more people are now receiving a diagnosis of a RCD. Although individually rare, collectively they affect at least 1 in 200 live-born babies. This is a real challenge, causing a huge increase in demand as no other charity covers such a range of conditions.

As the disorders are individually rare, there remains a lack of knowledge and understanding about them among many health and other professionals. Parents describe receiving a diagnosis of a RCD for their child as a "sledgehammer blow" and with complex terminology and very uncertain outcomes, they inevitably have lots of questions. Many go unanswered though, adding to their distress and sense of desperate isolation. This is where Unique (and often only Unique), can help.

Activities and achievements

This section summarises the key strands of our work, to meet the charity's aims as described above.

1. Supporting families

To help parents and carers begin to understand and come to terms with their child's diagnosis and its complex medical, genetic and genomic terminology, our family support services include:

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Report of the trustees

For the year ended 31 March 2020

- **The Unique Listening Ear telephone and email help service** – a first point of contact for distressed parents, our experienced team are able to explain the diagnosis, answer many of their questions and go through what the future may hold for their child, including the health and other issues they are likely to face and the help they could need.
- **Our Family matching service** - using our confidential database to link families living with similar conditions or facing similar challenges. Mutual support and understanding can be hugely beneficial.
- **Family Events** such as our regional family days, bringing local families together to meet others and develop support networks, along with expert professionals including clinical and laboratory-based geneticists, furthering our knowledge and helping families access information and other resources.

2. Providing specialist information

Parents and carers need reliable, understandable information to answer their many questions. Through our **Unique Information Project** two of our part-time Information Officers, both post-doctoral geneticists, produce a range of information guides to specific disorders. They are written in a family-friendly, accessible way and independently medically-verified prior to publication by experts in the field who volunteer their time. They are based on data provided by Unique member families and information gathered through research into the often limited medical literature. A unique resource of their type, all are free of charge in digital or paper format and cover health issues related to a specific RCD plus relevant topics such as learning and behaviour.

We also publish '**practical guides**' for families covering issues such as sleep, toilet training and continence, looking after your child's teeth, feeding, communication, leisure and days out. These are all based on issues families tell us are relevant and important to their daily lives.

Our Unique database/patient registry contains rich data provided by our member families. In addition to 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 and produce our information guides.

3. Networking to raise awareness

Only with increased networking and continued awareness-raising can we improve the knowledge and understanding of RCDS. Over many years, we have built strong relationships with geneticists and medical professionals across the UK and beyond and work closely with 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 reach a diverse range of audiences including policy makers, medical and other professionals, funders and family members. We sit on a variety of relevant advisory and policy boards, from national down to local level and have a network of over 200 local volunteer contacts, many of them parents themselves, who help signpost families to local services and resources.

Key to our 5-year operating plan is a digital upgrade and through our very active **Social Networks** we promote the charity, raise funds and support families in safe, supportive, moderated environments. Our fully mobile-responsive website has lots of free information and resources and an online form makes it much easier for new families to join us and receive the help they need.

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Report of the trustees

For the year ended 31 March 2020

Achievements during 2019-2020

Covid-19: As this report covers the period to 31 March 2020 and the UK's lockdown only began towards the end of March 2020, the effects of the global pandemic on our performance during the financial year were minimal. None of the fundraising events our supporters were due to take part in had been cancelled by this point. We were also, for example able to go ahead with our successful family day in Southampton in early March 2020 (detailed below), with measures in place such as hand sanitising and requesting people with any Covid symptoms stay away from the event.

1. Supporting families

2,701 new families came to us during the year as demand continued at very high levels. Though slightly down on the previous year (2,802), this is still way ahead of the average for the previous 5 years (1,449). This took our total membership to 21,968 families, representing over 24,500 individuals affected by RCDs. Our staff continue to meet this steep, upward curve with the professionalism, empathy and patience that has become our hallmark.

We bolstered our Listening Ear telephone and email helpline team and capacity to help even more families by recruiting a further part-time Information Officer. Collectively, the team answered:

- **10,406 emails** from families in need of help;
- **407 telephone calls** from families and others;
- **1,622 enquiries** from medical and other professionals; and
- **1,066 messages asking for our help** via our public Facebook page.

Social media is the fastest growing medium by which people contact us and the 1,066 message queries received via our public Facebook page represents a more than 50% increase on the previous year. We are continuing to adapt the ways in which we work as families' contact preferences change.

We ran three more Unique Family Days, in Newcastle and Leeds in the Autumn of 2019 for families in the North East and Yorkshire and in Southampton in early Spring 2020 for families in Hampshire, Dorset and surrounding areas. Each was successful and enjoyable and attended by approximately 500 parents, carers and children in total across the three days (including siblings of those affected). We were also delighted to be joined by geneticists and healthcare scientists who generously gave up their free time. With children's entertainment and lunch provided for all, families were able to meet and get to know others and learn more about genetics and genomics in a relaxed, non-judgmental and fun environment.

Our Family Support Officer provided all new families with a welcome pack, resources and information and we linked many hundreds of Unique member families for mutual support.

2. Providing specialist information

This year, we increased our capacity to produce the information that is so vital to families. Two of our part-time Information Officers, assisted by an army of volunteers published:

- **24 brand new information guides** to specific rare chromosome and single gene disorders, up from 13 in 2018-19 and taking our total to over 300;
- **11 substantial updates to our existing guides** including new information provided by member families and using the latest published medical research; and

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For the year ended 31 March 2020

- **49 more guides were translated by expert volunteers into a variety of languages** for those for whom English is not their first language. This year we added guides in Chinese and Korean for example and now have guides in 14 languages, also including Arabic, French, German, Spanish and Russian. Reaching out to non-English speaking families expands our pool of families from whom to gain knowledge of the effects of RCDs and to whom we can link our existing families.

Our 'practical guides' continued to be very popular with families and **we published a new 'Therapies' guide** to introduce families to the many different types of therapy available and which other families tell us have worked for them. As the Covid-19 'Lockdown' began in March 2020, we also published a brand new guide to help families with **self-isolation**, which proved very popular.

We also published a **brand new booklet, entitled 'My Chromosome Story'**, an easy read picture book for children and a **new 'quick read' guide** explaining how we produce information, what we aim to do and the sorts of thing we include.

We **work in collaboration** with other charities and support groups to develop collective knowledge and resources whenever possible. This year we joined the 'Embracing Complexity' coalition of c. 50 charities concerned with neurodevelopmental conditions and mental health issues. For the benefit of families affected by RCDs we continued to work with Genetic Alliance UK and smaller groups such as the KBG Syndrome Support Group and the CLCN4 Support Group.

We continued our rolling programme of updating all data held in our patient registry/database. The data 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.

3. Networking to raise awareness

A first for Unique and a highlight of the year was hosting two trainee genomic counsellors (for one and two weeks, respectively), both of whom are on the Scientist Training Programme delivered by Health Education England and the National School for Healthcare Science. The elective component to the training course means time with us is an invaluable learning experience, helping develop an understanding of the daily challenges families face. This will provide longer-term benefits for their clinical practice and patients as well as their wider teams and we will look to replicate it in future.

Our CEO, Dr. Beverly Searle, continued to participate in the DHSC UK Rare Diseases Policy board throughout the year as one of two patient representatives, focussing on a new, overarching post-2020 framework for rare diseases.

Our Information Officer Dr. Sarah Wynn is involved in the British Society for Genomic Medicine's (BSGM) Bioethics & Policy Committee, on the working party for guidance for genetic testing of children and new guidance on pre-natal testing.

Our Information Officers Arti Patel and Francesca Wicks presented at the Festival of Genomics in London, about Unique's work with families and how we assist and educate genomics professionals.

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Report of the trustees

For the year ended 31 March 2020

Dr. Searle was invited to give a presentation at the first workshop of the Pan-European network '**Enhancing Psychiatric Genetic Counselling**' (**EnGagE**) which aims to strengthen research into the newly-emerging disciplines of Psychiatric Genetic Counselling and Psychiatric Genetic Testing to facilitate their implementation into routine clinical care.

Our C.O.O. Craig Mitchell sits on the project advisory (steering) group of the Cerebra/Cardiff University project '**Improving Mental Health in Children with Rare Genetic Conditions.**'

We had awareness-raising stands at conferences including the British Paediatric Neurology Association and the **World Congress on Genetic Counselling**, helping to spread the word about Unique's work to a wider, professional audience.

During the year we passed **34,000 followers on our public Facebook page** and **6,500 Twitter followers**. We also have **more than 3,000 followers to our Instagram**. Our digital marketing is a key part of our networking, awareness-raising, disseminating information, supporting families and fundraising. Many families now find Unique, and therefore the support they need, via social media.

The sixth **Rare Chromosome and Gene Disorder Awareness Week** took place in June 2019, with the theme 'Celebrate and Educate'. Lots of people took part, giving presentations, holding coffee mornings, cake sales and other events. Several corporate supporters helped promote the week via their websites and email footers and held fundraisers and a number of schools took part in our colouring competition. Lots of members fundraised in person or virtually via Facebook and our own Facebook fundraiser raised over £2,600. We were delighted that so many of our members and supporters really got behind the week and they certainly helped us to 'celebrate and educate'!

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.

Infrastructure

trustees and staff continued to ensure Unique's infrastructure is fit for purpose. Data security is paramount, with sensitive medical information accessed and processed by staff on a hierarchical basis. All data are processed in accordance with the General Data Protection Regulation (GDPR). During the year systems were put in place and reinforced, allowing some staff to work securely from home and also reduce postal expenditure by contacting families more securely by encrypted email.

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;

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Report of the trustees

For the year ended 31 March 2020

- 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 2019-20

Income

Our total income for the year is £323,842. Whilst this is a decrease on our income from the previous year (£391,978) which was our best ever, it is still a relatively healthy performance in uncertain times. Unrestricted income from donations and fundraising from members and supporters, corporate, trusts and foundations totalled £313,192. This means funds can be directed to where trustees feel they would be most beneficial and avoids a reliance on restricted funds for specific projects, which can be for a relatively short, fixed-term and have strict constraints. From charitable trusts and foundations, we received unrestricted funding of £33,041 and restricted income of £10,650. 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 £331,472, a planned increase of £49,794. We continued to budget prudently but strengthened our infrastructure and capacity to serve those who need us. Trustees and senior staff met regularly during the year (in person and via conference call), monitoring financial performance to take action as necessary. Our robust financial management procedures mean we can continue to invest in staff, resources and infrastructure to ensure longer-term sustainability in the face of ever-increasing demand.

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 £105,000. Having ensured expenditure remained tightly under control, reserves at the end of the year are at £382,340, of which unrestricted reserves stand at £379,041. 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 again this year decided to designate £40,000 this year to protect the Listening Ear Telephone and Email helpline service as it is a crucial, frontline service, the first port of call for families.

Update: Unique's 5-Year Strategic Plan

Our 5 –year strategy, covering 2017-22 and underpins our activities. To help us better serve our beneficiaries, a digital upgrade is key to this and our fully mobile-responsive website has made it easier for families to join us and get help. During the year we have continued to expand our library of information resources, brought families together through our family matching service and family days and virtually via our private social media groups.

Staff and trustees are fully aware of our statutory responsibilities in the area of fundraising and we are registered with the Fundraising Regulator. Our policy continues to be to diversify our fundraising streams and this helps us avoid over-reliance on one particular strand of income. By minimising risk and taking a prudent approach, trustees seek to ensure Unique's long-term sustainability.

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For the year ended 31 March 2020

Potential impact of Covid-19 on future plans

During 2020-21, we were planning to run at least two, possibly three more of our popular regional family days. We have taken the decision to postpone planning for events in the South West and East Anglia until such time as these could be done with no (or minimal) risk to families, the professionals who voluntarily give up their time to attend or Unique staff. It is highly unlikely therefore that these events will happen in 2020-21 and we are investigating whether we can replicate them virtually.

The Unique office was closed to staff towards the end of March 2020 and all those not furloughed will work exclusively from home. This will continue for the foreseeable future. A post-out of database forms, asking members to update their data, which forms the basis of much of the information we can provide about rare chromosome and single gene disorders, has been postponed. This will impact our ability to produce new information for families and professionals. Awareness-raising is crucial but staff will not be able to attend meetings in person, give presentations or undertake other awareness-raising activities until such time as it is safe for them to do so or there are virtual alternatives in place.

As a charity, we hold a London Marathon Golden Bond but with the event not taking place as scheduled, this will impact on our fundraising. At the time of writing, it is entirely possible that other mass participation fundraising events we have places in such as the Great North Run and Great Manchester Run will not take place in 2020-21 so we will need to focus our fundraising efforts in other areas, e.g. voluntary donations. This will be monitored on an ongoing basis, as part of the monthly management accounts meetings described below.

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 and seven 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 formally three times per year, with senior staff present, with the charity's position kept under review at each meeting and at other times as necessary.

Towards the end of March 2020 (the end of the financial year and therefore the end of this reporting period), it became clear that the Coronavirus pandemic was likely to have a significant impact on the charity's funding and frontline services for the coming financial year (2020-21). Some mass participation fundraising events would have to be postponed or cancelled and the UK was about to go into a national lockdown.

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For the year ended 31 March 2020

In response, trustees and senior staff created an emergency, 'worst-case scenario' budget for 2020-21, assuming greatly-reduced voluntary income and few, if any fundraising activities. This budget included stress testing to measure our likely cash flow and the impact on free reserves throughout the next 12 months to March 2021. As part of this, all expenditure items were considered to ensure costs would be kept to a minimum and decisions could be taken to mitigate the impact of a reduction in income, for example moving to digital copies only of the Unique members magazine, rather than paper copies, saving on printing and postage costs. With some activities unlikely to take place and a predicted reduction in genetic testing meaning demand for some of our services will reduce, some staff will be furloughed under the UK government's Coronavirus Job Retention Scheme.

Moving forward, trustees and senior staff will hold monthly financial management meetings via Zoom, in addition to the formal trustee meetings. The management accounts for the previous month (and financial year to date) will be discussed to ensure trustees can react quickly, for example to further reduce costs where necessary or appropriate to protect the charity and its beneficiaries.

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, an 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 performance is kept under ongoing review, with a formal annual appraisal referencing their key responsibilities in relation to Unique's charitable aims. Training needs are identified and training sourced where appropriate.

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 other digital means, 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 nine trustees with diverse backgrounds including law, business, marketing, finance, accounting, IT, the charity sector, education and medicine. During the year Dr. Shwetha Ramachandrappa, a Consultant in Clinical Genetics and Genomics at Guy's and St. Thomas' NHS Foundation Trust joined the board, bringing a vital perspective to inform Unique's strategy and operations. New trustees are recruited by advertising as widely as possible and through our own networks 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 October 2019 in central London and are kept informed by the Company Secretary.

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Report of the trustees

For the year ended 31 March 2020

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.

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 December 2020 and signed on their behalf by

Helen Campbell - trustee (Chair)

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 2020 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 2020 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.

Date: 14 December 2020

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

Rare Chromosome Disorder Support Group

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

For the year ended 31 March 2020

	Note	Restricted £	Unrestricted £	2020 Total £	2019 Total £
Income from:					
Donations	3	-	303,240	303,240	324,409
Charitable activities:					
<i>Family support services</i>	4	7,400	-	7,400	31,027
<i>Information and awareness</i>	5	3,250	7,501	10,751	34,608
Investments		-	2,451	2,451	1,934
Total income		<u>10,650</u>	<u>313,192</u>	<u>323,842</u>	<u>391,978</u>
Expenditure on:					
Raising funds		-	38,982	38,982	41,894
Charitable activities:					
<i>Family support services</i>		17,731	156,342	174,073	140,267
<i>Information and awareness</i>		3,956	114,416	118,372	99,472
Total expenditure	6	<u>21,687</u>	<u>309,740</u>	<u>331,427</u>	<u>281,633</u>
Net income / (expenditure) and net movement in funds	7	(11,037)	3,452	(7,585)	110,345
Reconciliation of funds					
Total funds brought forward		<u>14,336</u>	<u>375,589</u>	<u>389,925</u>	<u>279,580</u>
Total funds carried forward		<u><u>3,299</u></u>	<u><u>379,041</u></u>	<u><u>382,340</u></u>	<u><u>389,925</u></u>

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 16 to the accounts.

Rare Chromosome Disorder Support Group

Balance sheet

As at 31 March 2020

	Note	£	2020 £	2019 £
Fixed assets				
Tangible fixed assets	10		3,270	3,284
Investments	11		<u>700</u>	<u>700</u>
			3,970	3,984
Current assets				
Stock	12	2,608		1,147
Debtors	13	10,195		16,673
Cash at bank and in hand		378,719		<u>380,244</u>
		391,522		398,064
Creditors: amounts due within 1 year	14	13,152		<u>12,123</u>
Net current assets			378,370	<u>385,941</u>
Net assets	15		382,340	<u>389,925</u>
Funds				
Restricted income funds	16		3,299	14,336
Unrestricted funds:				
Designated funds			40,000	40,000
General funds			339,041	<u>335,589</u>
Total charity funds			382,340	<u>389,925</u>

The financial statements have been prepared in accordance with the special provisions relating to companies subject to the small companies regime within Part 15 of the Companies Act 2006.

Approved by the trustees on 11 December 2020 and signed on their behalf by

Helen Campbell - Trustee (Chair)

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2020

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. However, the COVID-19 pandemic has had a profound impact on the global economy, and has in turn affected the charity. The trustees have considered the impact of this issue on the charity's current and future financial position. The charity holds unrestricted, general reserves of £339,041 (in line with the reserves policy), designated reserves that can be drawn down if necessary of £40,000 and a cash balance of £378,719. The trustees therefore consider that the charity has sufficient cash reserves to continue as a going concern for a period of at least 12 months from the date on which these financial statements are approved.

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.

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.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2020

1. Accounting policies (continued)

d) Donated services and facilities (continued)

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.

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 and governance 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:

	2020	2019
Raising funds	8%	9%
Family support services	45%	43%
Information and awareness	47%	48%

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
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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.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2020

1. Accounting policies (continued)

l) 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.

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 depreciation as described in note 1 (i) to the accounts.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2020

2. Prior period comparatives

	Restricted £	Unrestricted £	2019 Total £
Income from:			
Donations	810	323,599	324,409
Charitable activities			
<i>Family support services</i>	31,027	-	31,027
<i>Information and awareness</i>	29,859	4,749	34,608
Investments	-	1,934	1,934
Total income	61,696	330,282	391,978
Expenditure on:			
Raising funds	-	41,894	41,894
Charitable activities			
<i>Family support services</i>	22,637	117,630	140,267
<i>Information and awareness</i>	31,153	68,319	99,472
Total expenditure	53,790	227,843	281,633
Net income and net movement in funds	7,906	102,439	110,345

3. Donations

	Restricted £	Unrestricted £	2020 Total £
Grants more than £5,000:			
D & J Hunter Charitable Trust	-	10,000	10,000
Grants £5,000 or less	-	23,041	23,041
General donations	-	48,888	48,888
Corporate donations	-	15,731	15,731
Overseas donations	-	11,601	11,601
Gift aid	-	24,785	24,785
Give As You Earn (GAYE)	-	1,418	1,418
Pyramids	-	491	491
Donations from fundraising activities	-	167,285	167,285
	-	303,240	303,240

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2020

3. Donations (continued)

Prior year comparative

	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
	<u>810</u>	<u>323,599</u>	<u>324,409</u>

4. Charitable activities: family support services

	Restricted £	Unrestricted £	2020 Total £
Grants £5,000 or less	<u>7,400</u>	<u>-</u>	<u>7,400</u>

Prior year comparative

	Restricted £	Unrestricted £	2019 Total £
Grants £5,000 or less	<u>31,027</u>	<u>-</u>	<u>31,027</u>

5. Charitable activities: information and awareness

	Restricted £	Unrestricted £	2020 Total £
Grants £5,000 or less	3,250	-	3,250
Christmas card and merchandise sales	-	7,001	7,001
Participation in research	-	500	500
	<u>3,250</u>	<u>7,501</u>	<u>10,751</u>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2020

5. Charitable activities: information and awareness (continued)

Prior year comparative

	Restricted £	Unrestricted £	2019 Total £
Grants £5,000 or less	29,859	-	29,859
Christmas card and merchandise sales	-	4,749	4,749
	<u>29,859</u>	<u>4,749</u>	<u>34,608</u>

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2020

6. Total expenditure

	Raising funds £	Family support £	Information and awareness £	Support and governance £	2020 Total £
Audit and accountancy	-	-	-	3,720	3,720
Computer expenses	395	3,345	2,772	26	6,538
Depreciation	136	817	852	9	1,814
Insurance	-	-	-	2,433	2,433
Office costs and rent	1,549	10,745	10,070	267	22,631
Postage and distribution	339	11,939	1,998	108	14,384
Printing and design	229	6,568	3,899	4	10,700
Event costs	-	11,521	235	-	11,756
Staff costs (note 8)	24,569	112,229	74,287	22,475	233,560
Stationery	64	1,150	834	4	2,052
Subscriptions, licences and charges	9,341	122	3,975	60	13,498
Training and other staff costs	4	148	24	347	523
Travel and subsistence	46	1,608	1,236	169	3,059
Website and database development	18	526	4,072	143	4,759
Sub-total	36,690	160,718	104,254	29,765	331,427
Allocation of support and governance costs	2,292	13,355	14,118	(29,765)	-
Total expenditure	38,982	174,073	118,372	-	331,427

Governance costs were £6,153 (2019: £6,145).

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2020

6. Total expenditure (continued) Prior year comparative

	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 8)	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	-	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	-	281,633

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2020

7. Net movement in funds

This is stated after charging:

	2020	2019
	£	£
Depreciation	1,814	3,945
Trustees' remuneration	Nil	Nil
Trustees' reimbursed expenses	Nil	Nil
Auditors' remuneration:		
▪ Statutory audit (including VAT)	<u>3,720</u>	<u>3,600</u>

8. Staff costs and numbers

Staff costs were as follows:

	2020	2019
	£	£
Salaries and wages	210,774	177,459
Social security costs	14,893	11,896
Pension contributions	<u>7,893</u>	<u>6,718</u>
	<u>233,560</u>	<u>196,073</u>

No employee earned more than £60,000 during the year (2019: 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 £93,637 (2019: £90,437).

	2020	2019
	No.	No.
Average staff head count	10.00	9.00
Average full time equivalent	<u>7.00</u>	<u>6.00</u>

9. Taxation

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2020

10. Tangible fixed assets

	Computer equipment £
Cost	
At 1 April 2019	16,264
Additions in year	<u>1,800</u>
At 31 March 2020	<u>18,064</u>
Depreciation	
At 1 April 2019	12,980
Charge for the year	<u>1,814</u>
At 31 March 2020	<u>14,794</u>
Net book value	
At 31 March 2020	<u><u>3,270</u></u>
At 31 March 2019	<u><u>3,284</u></u>

11. Investments

	Artwork £
At 31 March 2020	<u><u>700</u></u>
At 31 March 2019	<u><u>700</u></u>

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 satisfied that the print is carried at an appropriate value at 31 March 2020.

12. Stock

	2020 £	2019 £
Merchandise	<u><u>2,608</u></u>	<u><u>1,147</u></u>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2020

13. Debtors

	2020 £	2019 £
Trade debtors	122	200
Prepayments	7,636	7,651
Accrued income	2,437	8,822
	<u>10,195</u>	<u>16,673</u>

14. Creditors : amounts due within 1 year

	2020 £	2019 £
Trade creditors	-	510
Accruals	7,673	6,916
Other taxation and social security	4,473	3,973
Pension creditor	1,006	724
	<u>13,152</u>	<u>12,123</u>

15. Analysis of net assets between funds

	Restricted funds £	Designated funds £	General funds £	Total funds £
Tangible fixed assets	-	-	3,270	3,270
Investments	-	-	700	700
Net current assets	3,299	40,000	335,071	378,370
Net assets at 31 March 2020	<u>3,299</u>	<u>40,000</u>	<u>339,041</u>	<u>382,340</u>

Prior year comparative

	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	<u>14,336</u>	<u>40,000</u>	<u>335,589</u>	<u>389,925</u>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2020

16. Movements in funds

	At 1 April 2019 £	Income £	Expenditure £	At 31 March 2020 £
Restricted funds				
Family support services	13,630	7,400	(17,731)	3,299
Information and awareness	706	3,250	(3,956)	-
Total restricted funds	14,336	10,650	(21,687)	3,299
Unrestricted funds				
<i>Designated funds:</i>				
Listening Ear Fund	40,000	-	-	40,000
<i>Total designated funds</i>	<u>40,000</u>	<u>-</u>	<u>-</u>	<u>40,000</u>
General funds	335,589	313,192	(309,740)	339,041
Total unrestricted funds	<u>375,589</u>	<u>313,192</u>	<u>(309,740)</u>	<u>379,041</u>
Total funds	<u><u>389,925</u></u>	<u><u>323,842</u></u>	<u><u>(331,427)</u></u>	<u><u>382,340</u></u>

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, including Awards for All, the Mary Homfray Charitable Trust and the George A Moore Foundation, 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

These funds are provided by a number of charitable trusts and foundations, helping us to continue to increase our library of 'practical' information guides for families and supporting our work to provide families with specialist information as part of our wider service.

Purposes of designated funds

Listening Ear Fund

The trustees have designated £40,000 from general funds to the charity's 'Listening Ear' project. This sum is 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.

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2020

16. Movements in funds (continued)

Prior period comparative

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

17. Operating leases

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

	2020 £	2019 £
Amount falling due:		
Within 1 year	-	7,500
Within 2 - 5 years	<u>-</u>	<u>-</u>

18. Related party transactions

There were no related party transactions during the year ended 31 March 2020, or the prior year.

19. Financial instruments held at fair value

	2020 £	2019 £
Financial assets measured at fair value	<u><u>700</u></u>	<u><u>700</u></u>

Financial assets measured at fair value comprise investment assets.