Company no. 05460413
Charity no. 1110661

Rare Chromosome Disorder Support Group

Report and Audited Financial Statements

31 March 2017

Rare Chromosome Disorder Support Group

Contents

For the year ended 31 March 2017

Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2017

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
Sally Cohen	Vice Chair
Edna Knight, MBE	Founder, Life President
Fiona de Zoete	Trustee
Isobel Hindle	Trustee
Gillian Manvell	Trustee
Sophie Sainty	Trustee
Benjamin Stern	Trustee

Chief executive officer	Beverly Searle, PhD
Company secretary	Craig Mitchell MInstF (Dip)
Chief medical advisor	Professor Maj Hulten
Patrons	Professor Dian Donnai, UK Professor Jean-Pierre Fryns, Belgium Professor Judith Hall, Canada Baroness Neville-Jones, UK Professor Albert Schinzel, Switzerland

Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2017

Bankers

Charities Aid Foundation
Kings Hill
West Malling
Kent
ME19 4TA

United Trust Bank
One Ropemaker Street
London
EC2Y 9AW

Lloyds
PO Box 545
Faryners House
25 Monument Street
London
EC3R 8BQ

Virgin Money
Jubilee House
Gosforth
Newcastle upon Tyne
NE3 4PL

Yorkshire Building Society
73 Station Road East
Oxted
RH8 0AX

Auditors

Godfrey Wilson Ltd
Chartered accountants and statutory auditors
5th Floor, Mariner House
62 Prince Street
Bristol
BS1 4QD

The trustees present their report and the audited financial statements for the year ended 31 March 2017.

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).

The genomics revolution means many more families are now receiving an explanation for their child's difficulties. The increased use of DNA sequencing technology in clinical practice, together with the advances made by the Deciphering Development Disorders (DDD) study and 100,000 Genomes project, has resulted in an exponential increase in the number of families being provided with a genomic diagnosis. The resultant increase in demand for our services means that Unique membership now stands at more than 15,000 member families representing over 17,000 affected individuals.

At the same time, technology continues to change the way we all engage with each other, whereas in the past our members may have contacted us and waited for the post to deliver a copy of Unique's Little Yellow Book, they now expect instant and in-depth access to knowledge and answers to their many questions. The impact of social media, the ability it provides to reach a wide and diverse audience is also a factor we need to consider and continue to embrace, whilst being conscious of its potential to fragment our members into niche groups.

The Trustees have been considering the challenges and opportunities presented to us by these scientific and technological changes and have developed a five year strategic plan. We defined five strategic aims:

- Being better together – we will bring people together via events such as study weekends and family days, reduce the fragmentation created by families joining much smaller, disorder-specific virtual groups and promote the value of Unique as a cohesive community for its members and as a powerful voice in the genomics world.

- Improved lifetime support – Unique needs to be there for our member families at critical times throughout their lives. We will develop more tailored support and advocacy for families, promote local groups with local champions and look to develop a mentor scheme.

- Improved information and understanding – our first key initiative in developing and expanding our information resources has been to commission the development of a new, improved website. Work has begun on this and it will launch within the next financial year.

- Improved efficiency – we need to provide our services to more members and so we need to work smarter. During the next year we will undergo a digital update, with secure access to and storage of data of paramount importance.

- Sustainability – we need to ensure we continue to be a viable organisation to deliver the services our members need throughout their lifetime. To support this we will develop and implement a new fundraising strategy.

The charity sector is continuing to deal with the fallout from negative media coverage regarding fundraising practices and the past year saw a series of political shocks with the EU referendum and the US & UK elections. We live in a time of change and challenging the norm and a small, niche charity such as Unique needs to be receptive to these changes and adapt. There appears to be a resurgent appetite, at least in the UK, to get involved in social issues and an increased desire to want to make a difference. Hopefully Unique will be able to benefit from this and in order to do so we need to continue to raise awareness of rare chromosome and gene disorders.

We continue to be humbled by the reliable and enduring generosity of the families and individuals who fundraise for us, many of whom do so whilst caring for disabled children and we hope that we can continue to provide and improve the services they require and deserve.

Sadly during the year we lost Prisca Middlemiss, our Senior Information Officer, after a long illness. Prisca had joined Unique in 2003 and wrote many of our family-friendly guides to specific disorders, as well as personally helping a huge number of families. Prisca was dedicated and talented. She took the complex science behind rare chromosome and gene disorders and presented it to families looking for explanations and guidance in straightforward language. She was brave and fearless throughout her own illness and she inspired all of us at Unique. Prisca was still working with us until a few weeks before she died and she was instrumental in recruiting two new Information officers to continue her work and during the year we welcomed Dr. Anna Pelling and Dr. Claire Andersen to the team. Both are highly qualified and we are privileged that they have chosen to join us as we continue with the next stages of Unique's development.

Helen Campbell, Chair of Trustees, July 2017

Rare Chromosome Disorders

Rare Chromosome and Gene Disorders (RCDs) are lifelong conditions, present at birth, in which parts of one or more of a person's chromosomes are missing, added on or rearranged. There is currently no cure. Though individually rare (some literally unique), collectively they affect at least 1 in 200 live-born babies, often causing severe learning and physical disabilities. Many of those affected will be totally reliant on their parents and carers throughout their lives. Others are only affected relatively mildly and find out they have a disorder only when they try to have children of their own and experience issues such as problems conceiving and multiple miscarriages.

Technology used to diagnose RCDs has moved forward rapidly in recent years and many more people are now receiving a diagnosis. Despite this, the rarity of individual conditions means there remains a lack of knowledge and understanding about them among many doctors and other health professionals. Parents struggling to understand and come to terms with a complex diagnosis for their child inevitably have lots of questions but many go unanswered, exacerbating their feelings of distress, isolation and worries for the future. This is where Unique comes in.

Vision and Mission Statement

Unique's vision is of a world where all families who have a member with a rare chromosome or gene disorder receive the understanding, care, support and information that they need.

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

Aims and Objectives

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

Unique provides specialist information and support to the parents and carers of those affected. We help them to understand their child's diagnosis and begin to come to terms with it so they can face the future with renewed hope. Many medical and other professionals value our work so highly they signpost families to Unique as a first point of contact. We also work to raise awareness of the disorders among professionals and the public to develop a better understanding and appreciation of the daily challenges faced by those affected and their families.

Unique's Core Services: Family Support and Specialist Information

To understand their child's diagnosis of a RCD, parents and carers need to have complex terminology explained in an easy to understand way. A majority also need someone to listen to and empathise with them. Family Support and Specialist Information are therefore the key strands of the services we provide:

Family Support Services:

- **The *Unique* Listening Ear** telephone and email helpline is often the first point of contact for distressed parents of a newly-diagnosed child. Our experienced staff members empathise with parents, answer their questions and clearly explain complex terminology to help them understand their child's diagnosis. Medical and other professionals also contact us for information to help them counsel patients, monitor for conditions associated with a particular RCD and plan patient care.
- ***Unique's* Family matching service** links those living with similar conditions or facing similar challenges to facilitate invaluable mutual support.
- **Family Events** such as our regional family days, disorder-specific study days and family conference weekends are an opportunity for families to meet and get to know others in a similar position and develop lasting support networks. By bringing families and expert professionals together, these events also help to further our knowledge and understanding of RCDs and help families access information and other resources.
- **Networking** via our very active, moderated social media groups is a huge hit with families. They are safe, supportive environments for swapping tips, sharing information, and offering support to those in need.

Specialist Information:

- Through the ***Unique* information project** we have produced a library of over 200 information guides to specific rare chromosome and single gene disorders. All are available free of charge from our website or in hard copy from Unique staff. Designed to be family-friendly, they are based largely on evidence provided by Unique members, in conjunction with data gleaned from the often limited published medical literature. Geneticists and other expert professionals volunteer their time to independently medically verify each guide prior to publication. We also have 14 'practical guides' for families on general but highly relevant topics, for example what to do once you have received a diagnosis and preparing for a genetics appointment.

- The ***Unique*** **database/patient registry** is at the heart of the service we provide. The data provided by member families goes far beyond the purely medical to include behavioural, social, educational and developmental information. It is used anonymously to assist and inform researchers, geneticists and other professionals in their work and our helpline team use it to guide families on the likely effects of their child's condition. Sensitive medical information is only accessed on a hierarchical basis, is held securely and treated in the utmost confidence, in accordance with the Data Protection Act.
- Our **website, www.rarechromo.org** has HonCode ('Health on the Net' Code) accreditation and is full of regularly updated information and resources.
- The **Unique magazine** is published three times per year and highly valued by Unique families, many of whom contribute their own articles to help others. Each edition has lots of articles of interest, tips, resources and fundraising ideas.
- Our **network of over 200 local volunteer contacts** helps us support families in their area, using invaluable local knowledge to signpost them to local services and resources.

Public Benefit

The Trustees confirm that they have had due regard for the Charity Commission Guidance on public benefit when reviewing the charity's aims, objectives and activities undertaken as well as in 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 information not available elsewhere as well as softer support.

For the wider public benefit, we have actively supported the development of next generation DNA sequencing to provide families with a diagnosis of a rare disease, most notably through the UK DDD and 100,000 Genomes projects. Dr. Searle sits on NHS England's Genomics Project Programme Board and Rare Disease Transistion Working Group, on the Department of Health's Rare Disease Policy Board and has participated in recent all-party parliamentary hearings into the implementation of the UK strategy for rare diseases which will benefit many thousands of patients and their families. The genomics expertise gained has the huge potential to benefit more mainstream areas of medicine, e.g. cardiology and respiratory medicine and to deliver personalised medicine.

Activities and Achievements during 2016-17

During the year 1,465 new member families joined us, compared to an average of 1,274 for the five years prior to 2016-17, a 15% increase. Total membership at the end of March 2017 stood at over 15,000 families, representing well over 17,000 individuals with a RCD.

As more and more professionals become aware of our work and tell us how highly they value it, they increasingly refer families to us as a first point of contact. This, coupled with ongoing improvements to diagnostic technology and our own awareness-raising, mean that rapid increases in demand for our services have continued. Trustees are proud of the professional and dedicated way in which the Unique staff, led by Dr. Beverly Searle, have responded. Key achievements during the year were:

1. Information:

"I just wanted to thank you for such a comprehensive guide. My son is 11, and I've never found so much information about his rare condition, that was so clear, understandable and with real people and faces included. Suddenly, I don't feel so alone."

- Our two part-time Information Officers produced 21 new information guides to specific RCDs. This included 10 guides to novel single gene disorders which have only recently become detectable with newly-improved technology.
- We substantially revised and updated 8 of our existing information guides with lots of the information provided by member families themselves.
- Reflecting the needs of our diverse community, 27 more of our information guides were translated into languages such as Arabic, Polish, German, Spanish and Russian, to help those for whom English is not their mother tongue. Translations are undertaken entirely by volunteers, overseen by the Unique team and we are extremely grateful for their efforts.
- Dr Claire Andersen who has a PhD in Immunology and a first class honours degree in Human Genetics, with a background in research and as a teacher of Science, was recruited to a part-time role as an Information Officer to work with Dr. Anna Pelling to write and publish the information guides.

2. Support:

"Unique provided us with amazing understanding and support and suddenly we weren't on our own any more."

- Our Listening Ear team answered over 10,200 telephone, email and social media queries from families, plus a further 1,900 from medical and other professionals.
- The project to convert all historical paper records to secure, fully-indexed and filed electronic copies was completed. All staff now have access to these electronic records in real time. Records contain data supplied by families on a huge range of RCDs. This new system saves time when searching for specific information and negates the need to store a huge amount of paper copy. The Trustees are extremely grateful to Gemma Mitchell for her hard work in completing this vital project.
- We continued to update database entries for member families during the year. The information they provide is used to answer queries, produce information guides, match families and support health professionals and researchers.
- Unique's Family Support Officer's vast knowledge and experience of the practical consequences of RCDs and the wider disability sector continued to greatly benefit families in need.
- We continued to provide our 'Unique awareness card' to parents and carers to explain their child's condition. Hundreds more 'Unique Awareness cards' were provided to parents and carers to help explain their child's condition, e.g. when queuing in shops or travelling to explain their challenges.
- We were delighted to once again receive HONCode accreditation for the Unique website, showing it is a trustworthy source of health information.
- We successfully re-applied to the Google Grants programme, enhancing our online presence through pay per click advertising which is provided free of charge.

3. Networking:

- We held the first ever Unique events in Scotland (Glasgow) and Northern Ireland (Belfast), bringing together local families to relax and meet others in a supportive, non-judgmental environment. Each event was attended by over 80 adults and 50 children as well as clinicians and healthcare scientists from regional genetics centres who gave demonstrations about genetic testing and answered questions from parents.
- We also held a further successful event for families in the East Midlands.
- Together with a volunteer family member, we organised and ran the first ever study weekend for families with children affected by Koolen-de Vries Syndrome. Attended by Dr. David Koolen from the Netherlands, after whom the syndrome is named, the event was a huge success, helping families learn more about the syndrome, meet others living with it and attend workshops on topics of real relevance such as Speech and Language and Sleep issues.
- We continued to work closely with other third sector organisations, for example as active members of Genetic Alliance UK and Rare Disease UK.
- The Unique Facebook 'Cafe', a secret group providing a safe, supportive network for families reached 4,500 members. This post-moderated group, together with our local Facebook groups, is a lifeline for families, helping them overcome isolation, discuss resources, swap tips and interact with Unique staff for help. This continues to be an effective way of working, relieving some of the pressure from frontline services.
- We reached the milestone of 5,000 followers of our Twitter feed and continued our regular email news bulletins, reaching many thousands of members and supporters with news, resources, family events and fundraising ideas. All help families overcome their isolation as part of a supportive network.

4. Awareness-Raising and Collaboration:

- The third global Rare Chromosome Disorder Awareness Week took place in June 2016, built on the success of previous awareness weeks. This year we were able to secure some excellent media coverage, both in print and broadcast, across the UK, including a double page article in the Daily Record, Scotland's largest circulating daily newspaper.
- Dr. Searle was recruited to the NHS England Genomics Programme Board and the NHS England Rare Disease Transition Working Group. She was also successful in competition against six other candidates for one of two patient representative posts on the Department of Health's Rare Disease Policy Board.
- Dr. Searle also participated in All Party Parliamentary Group hearings into the implementation of the UK Strategy for Rare Diseases in England.
- Unique's Information Officer Arti Patel embarked on a 2 year part-time MSc Genomic Medicine course at St. George's Medical School in London.
- Dr. Searle gave presentations about the work of Unique and the challenges of living with a rare chromosome disorder in the family to a wide range of audiences including e.g. MSc Genomic Medicine students at Imperial, second year medical students at UCL, healthcare professionals in Brighton as well as families and professionals at conferences for 16p11.2 disorders and for PURA Syndrome and to the general public.
- Arti Patel presented to students at the University of Southampton undertaking the MSc in Genomic Medicine, as part of their Counselling skills for genomics module.
- Dr Anna Pelling gave a presentation at the Clinical Genetics Society Spring meeting in London.
- We participated in the first ever conference for families and professionals focusing on PURA Syndrome, a newly-discovered neurodevelopmental disorder related to the PURA gene.

Infrastructure

Trustees and staff continued to strengthen Unique's infrastructure during the year and we moved into a larger office within the same building. This facilitates effective, streamlined working practices and increased face to face contact between staff, some of whom work most of their hours from home. We continued to review our practices for data processing and storage, with one Trustee dedicated to working with senior staff to ensure the charity is ready for the changes in data protection legislation which will take effect from May, 2018.

Volunteers

We benefitted greatly from large numbers of volunteers during the year, including:

- More than 200 people volunteering as Unique local contacts, on hand to offer support to other members in their area and signpost them to local resources.
- Over 30 geneticists and other professionals verifying our information guides prior to publication.
- More than 30 other healthcare scientists, genomic technicians, clinical geneticists and therapists attending our family events to help answer technical questions from families.
- Volunteers translating our information guides into a variety of different languages.
- A number of others assisting in areas such as IT, marketing and promotional activities and despatching merchandise.
- Many hundreds more of our members, their friends and family and other supporters undertaking voluntary fundraising to raise the funds we need to provide our services.

Financial Review 2016-17

Income

Unique's income for the year is £325,118, a decrease of approximately 13% on the previous year but still relatively stable by comparison with prior years. Our unrestricted income is £309,245 much of which is through donations and fundraising by member families and supporters, as well as donations from corporates, trusts and foundations. Our proportion of unrestricted income is relatively high, meaning that Trustees can direct funds to where they are most needed. We are better able to plan for the future whilst not being reliant on third parties or statutory funding, which can often be for a fixed-term and tightly restricted. Our restricted income of £15,873 is to cover costs associated with the production of information guides to specific disorders, regional events for families in Northern Ireland, London and the South, regional funding to support families and professionals in Wales and the cost of purchasing two new printers.

Expenditure

Total expenditure for the year was £356,874, an increase of just over 9% on the previous year but comfortably within the budget we set at the beginning of the year. Trustees and senior staff met regularly during the year (in person and via conference call) to monitor financial performance and take action where necessary. We have sound and robust financial management procedures in place and have therefore been able to continue to invest in resources and infrastructure to ensure we can meet the needs of our beneficiaries.

The ascribed value of donated services for the year is £26,640. Throughout the year we were very grateful to continue to benefit from a Google Grant covering search engine advertising costs.

Level of Reserves

The Trustees have decided to adopt a policy of holding a minimum reserve equivalent to four months' average operating costs for the previous year (not including the value of donations in kind). This policy is reviewed annually. The Trustees have budgeted for reserves for the year 2017-18 of not less than £110,000.

As the charity sector continued to be buffeted by negative press and economic uncertainties, Trustees budgeted prudently to carefully control our expenditure. Reserves at the end of the year are at £306,843, with unrestricted reserves standing at £295,818. This means we can protect beneficiaries by safeguarding key services and ensure the charity's longer-term sustainability. Trustees have once again decided to designate £40,000 to protect the Listening Ear Telephone and Email helpline service. Some income received during 2016-17, e.g. grants received towards regional family days has been carried forward to 2017-18 when Regional Family Days will take place, for example in London, the North West and the South of England. There will also be significant expenditure on the development of a brand new Unique website during 2017-18.

The Future: Unique's New 5-Year Strategic Plan

With finite resources and as demand continues to increase rapidly, Trustees focused this year on developing Unique's strategy for the next five years. Our new strategic plan for 2017-22 has five over-arching themes. These set out the ways in which we will safeguard services, expand and improve our offering of support, information and networking for families at all stages of their affected relative's life. This will be underpinned by a complete digital upgrade, beginning with a brand new website to be developed and launched during 2017-18. We aim to develop innovative ways to expand our reach and help a variety of beneficiaries to access our services.

To ensure Unique is able to meet the needs of growing numbers of families who need our help, key areas for development include:

- Improving our support to families over the whole of their child's lifetime;
- Expanding our information resources and networks to families and involved professionals;
- Increasing awareness and understanding among policy makers and the general public;
- Further developing our awareness-raising activities, e.g. building on the successes of Chromosome Disorder Awareness Week;
- Running more events to bring families and professionals together – combating families' isolation and developing awareness and understanding of RCDs; and
- Undertaking a comprehensive digital upgrade of our information and systems.

Accordingly, with sufficient resources to continue to build our capacity to provide services our beneficiaries need, our future operational plans include:

- Holding regional family days in the North West of the UK, the South and in London as we continue this series of events across all areas of the country.
- Adding further information guides to our library of resources, including an expansion of the new series of guides to novel single gene disorders. We will also continue to expand our range of practical guides for families which cover more general but highly relevant topics.
- Continuing to invest in our staff to strengthen the charity's capacity to respond to and help all those who need us.
- Developing and building a brand new and fully mobile responsive website as part of our digital upgrade.
- Working with other organisations across the world on the fourth annual Rare Chromosome Disorder Awareness week, planned for June 2017.

Mindful of the ongoing uncertainties in a challenging climate for charities, we will continue to support and invest in fundraising across a diverse range of income streams, avoiding over-reliance on one particular strand. Trustees aim to minimise risk and ensure Unique's long-term sustainability to protect our beneficiaries. Our Chief Operating Officer (COO) is a member of the Institute of Fundraising and working with our Fundraising Officer, continues to focus on raising the funds we need to deliver services and develop a robust infrastructure for the charity.

As part of a planned, rolling programme, we will contact all member families to ask them to verify the information we hold and provide new information about their affected family member's RCD.

Structure, Governance and Management
Day-to-day management of the charity's activities is delegated by the Trustees to Dr. Beverly Searle, Chief Executive Officer (CEO). Unique currently employs a staff team of nine, including the CEO, three of whom are full-time, with the other six staff working part-time. Craig Mitchell (COO) is also Company Secretary.

Corporate and Social Responsibility and Sustainability
Unique's policy is to seek to reach 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, three 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 has been written during the year. This includes contingency plans as operating conditions and/or performance change. The Trustees meet four times per year and the charity's position is kept under review and discussed in detail 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 and Finance Officer have attended workshops provided by organisations such as the Charity Finance Group and ACAS to ensure we remain aware of our responsibilities in relation to regulatory compliance. All staff and trustees who come into contact with children as part of their roles undergo a DBS check as necessary.

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.

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 8 Trustees with diverse backgrounds including law, business, marketing, finance, accounting, the charity sector and education. Trustees are recruited by advertising as widely as possible, through our own and wider networks. The charity operates 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 Surrey in September 2016 and are kept informed by the Company Secretary.

Statement of Responsibilities of the Trustees

The trustees are required to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charitable company and the incoming resources and application of resources, including the net income or expenditure of the charity for the year. 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 estimates that are reasonable and prudent;
- state whether applicable 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 charitable company 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 charitable company 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 charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees confirm that to the best of their knowledge there is no information relevant to the audit of which the auditors are unaware. The trustees also confirm that they have taken all necessary steps to ensure that they themselves are aware of all relevant audit information and that this information has been communicated to the auditors.

Members of the charitable company guarantee to contribute an amount not exceeding £10 to the assets of the charitable company 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 6 October 2017 and signed on their behalf by

E. M Knight

Edna Knight - Trustee (Life President)

Helen Campbell

Helen Campbell - Trustee (Chairman)

Independent auditors' report

To the members of

Rare Chromosome Disorder Support Group

We have audited the financial statements of Rare Chromosome Disorder Support Group for the year ended 31 March 2017 which comprise the statement of financial activities, balance sheet, statement of cash flows and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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 and the charity's members as a body, for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of the trustees and auditors
As explained more fully in the trustees' responsibilities statement, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view.

Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors.

Scope of the audit of the financial statements
An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of whether the accounting policies are appropriate to the charitable company's circumstances, and have been consistently applied and adequately disclosed, the reasonableness of significant accounting estimates made by the trustees, and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the annual report to identify material inconsistencies with the audited financial statements. If we become aware of any apparent material misstatements or inconsistencies, we consider the implications for our report.

Opinion on financial statements
In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2017 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.

Opinion on other matters prescribed by the Companies Act 2006
In our opinion the information given in the trustees' annual report for the financial year for which the financial statements are prepared is consistent with the financial statements.

Independent auditors' report

To the members of

Rare Chromosome Disorder Support Group

Matters on which we are required to report by exception
We have nothing to report in respect of the following matters where 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 received all the information and explanations we require for our audit.

Alison Godfrey.

Date: 26 OCTOBER 2017.

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 2017

	Note	Restricted £	Unrestricted £	**2017 Total £**	2016 Total £
Income from:					
Donations and legacies	3	900	300,286	**301,186**	326,054
Charitable activities:					
Family support services	4	9,202	-	**9,202**	22,825
Information and awareness	5	5,771	6,403	**12,174**	21,452
Investments		-	2,556	**2,556**	3,390
Total income		15,873	309,245	**325,118**	373,721
Expenditure on:					
Raising funds		95	61,119	**61,214**	67,328
Charitable activities:					
Family support services		20,247	147,045	**167,292**	153,991
Information and awareness		4,973	123,395	**128,368**	105,425
Total expenditure	6	25,315	331,559	**356,874**	326,744
Net income / (expenditure)		(9,442)	(22,314)	**(31,756)**	46,977
Transfers between funds		-	-	-	-
Net movement in funds	8	(9,442)	(22,314)	**(31,756)**	46,977
Reconciliation of funds					
Total funds brought forward		20,467	318,132	**338,599**	291,622
Total funds carried forward		11,025	295,818	**306,843**	338,599

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.

Rare Chromosome Disorder Support Group

Balance sheet

As at 31 March 2017

	Note	£	2017 £	2016 £
Fixed assets				
Tangible fixed assets	11		**6,679**	8,709
Investments	12		**700**	700
			7,379	9,409
Current assets				
Stock	13	**1,711**		3,839
Debtors: amounts due within 1 year	14	**7,938**		8,108
Current asset investments		**-**		55,605
Cash at bank and in hand		**305,863**		274,437
		315,512		341,989
Creditors: amounts due within 1 year	15	**16,048**		12,799
Net current assets			**299,464**	329,190
Net assets	16		**306,843**	338,599
Funds	17			
Restricted income funds			**11,025**	20,467
Unrestricted funds:				
Designated funds			**40,000**	40,000
General funds			**255,818**	278,132
Total charity funds			**306,843**	338,599

Approved by the trustees on 6 October 2017 and signed on their behalf by

E. M Knight

Helen Campbell

Edna Knight - Trustee (Life President)

Helen Campbell - Trustee (Chair)

Rare Chromosome Disorder Support Group

Statement of cash flows

For the year ended 31 March 2017

	2017 £	2016 £
Cash used in operating activities:		
Net movement in funds	**(31,756)**	46,977
Adjustments for:		
Depreciation charges	**3,487**	3,258
Loss / (profit) on the sale of fixed assets	**157**	-
Decrease / (increase) in stock	**2,128**	(2,322)
Decrease / (increase) in debtors	**170**	2,186
Increase / (decrease) in creditors	**3,249**	(11,720)
Net cash provided by / (used in) operating activities	**(22,565)**	38,379
Cash flows from investing activities:		
Purchase of tangible fixed assets	**(1,614)**	(8,380)
Net cash provided by / (used in) investing activities	**(1,614)**	(8,380)
Increase / (decrease) in cash and cash equivalents in the year	**(24,179)**	29,999
Cash and cash equivalents at the beginning of the year	**330,042**	300,043
Cash and cash equivalents at the end of the year	**305,863**	330,042
Represented as:		
Current asset investments	**-**	55,605
Cash at bank and in hand	**305,863**	274,437
	305,863	330,042

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 the government and other grants, whether 'capital' grants or 'revenue' grants, 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 and is not deferred.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the exector(s) to the Trust 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 probably 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.

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:

Raising funds	13.6%
Family support services	32.5%
Information and awareness	53.8%

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.

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) Current asset investments
Current asset investments consist of cash held on deposit in interest bearing accounts. Such investments are measured at their fair value.

n) 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.

o) 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.

p) Financial instruments
The trust 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.

q) 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.

r) 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.

2. Prior period comparatives

	Restricted £	Unrestricted £	2016 Total £
Income from:			
Donations and legacies	7,217	318,837	**326,054**
Charitable activities			
Family support services	22,825	-	**22,825**
Information and awareness	10,924	10,528	**21,452**
Investments	-	3,390	**3,390**
Total income	40,966	332,755	**373,721**
Expenditure on:			
Raising funds	-	67,328	**67,328**
Charitable activities			
Family support services	11,925	142,066	**153,991**
Information and awareness	22,628	82,797	**105,425**
Total expenditure	34,553	292,191	**326,744**
Net income	6,413	40,564	**46,977**
Transfers between funds	-	-	-
Net movement in funds	6,413	40,564	**46,977**

3. Donations and legacies

	Restricted £	Unrestricted £	**2017 Total £**	2016 Total £
Grants > £5,000:				
D & J Hunter Charitable Trust	-	10,000	**10,000**	10,000
Grants from individuals	-	-	**-**	10,000
Grants < £5,000	700	2,350	**3,050**	3,000
Donated goods / services *	-	26,640	**26,640**	4,321
General donations	200	53,023	**53,223**	91,714
Corporate donations	-	25,234	**25,234**	22,187
Overseas donations	-	7,169	**7,169**	13,758
Gift aid	-	25,565	**25,565**	29,330
Give As You Earn (GAYE)	-	1,315	**1,315**	946
Pyramids	-	473	**473**	482
Legacy	-	3,053	**3,053**	-
Donations from fundraising activities	-	145,464	**145,464**	140,316
Total donations and legacies	900	300,286	**301,186**	326,054

* Donated services consist of the following:

	2017 £	2016 £
Google AdWords (free web advertising)	**26,640**	4,321

4. Charitable activities: family support services

	Restricted £	Unrestricted £	**2017 Total £**	2016 Total £
Grants > £5,000:				
Jeans for Genes	-	-	**-**	6,000
Big Lottery Fund Grant	-	-	**-**	5,825
DM Thomas Foundation for Young People	-	-	**-**	5,000
Grants < £5,000	9,202	-	**9,202**	6,000
Total family support services	9,202	-	**9,202**	22,825

5. Charitable activities: information and awareness

	Restricted £	Unrestricted £	**2017 Total £**	2016 Total £
Grants > £5,000:				
Oxford University	-	-	**-**	10,653
Grants < £5,000	5,771	-	**5,771**	271
Christmas card and merchandise sales	-	6,403	**6,403**	10,528
Total information and awareness	5,771	6,403	**12,174**	21,452

6. Total expenditure

	Raising funds £	Family support £	Information and awareness £	**2017 Total £**	2016 Total £
Staff costs (note 9)	32,165	95,268	79,953	**207,386**	193,668
Training and other staff costs	54	209	306	**569**	646
Postage and distribution	4,369	18,068	4,953	**27,390**	31,067
Printing and design	284	11,856	1,637	**13,777**	15,466
Stationery	243	779	882	**1,904**	2,143
Subscriptions, licences and charges	11,769	200	3,798	**15,767**	14,950
Travel and subsistence	115	3,167	958	**4,240**	4,820
Room hire and event costs	425	14,976	867	**16,268**	20,861
Computer expenses	3,875	2,850	3,504	**10,229**	7,915
Office costs	618	2,602	2,915	**6,135**	5,903
Office rent	2,384	5,450	9,196	**17,030**	15,000
Website and database development	3	177	13	**193**	121
Advertising **	3,625	8,668	14,347	**26,640**	4,937
Insurance	322	770	1,274	**2,366**	2,287
Audit and accountancy	454	1,085	1,797	**3,336**	3,702
Depreciation	488	1,116	1,883	**3,487**	3,258
Loss on disposal of fixed asset	21	51	85	**157**	-
Total expenditure	61,214	167,292	128,368	**356,874**	326,744

** Advertising represents primarily donated services with no cost to Unique (see note 3).

7. Support and governance costs

Support and governance costs are allocated to activities as follows:

	Raising funds £	Family support £	Information and awareness £	**2017 Total £**	2016 Total £
Staff costs	3,271	7,824	12,948	**24,043**	21,006
Training and other staff costs	54	124	209	**387**	324
Postage and distribution	534	1,221	2,061	**3,816**	4,043
Stationery	5	13	22	**40**	1,763
Subscriptions, licences and charges	58	138	229	**425**	212
Travel and subsistence	14	33	55	**102**	442
Room hire and event costs	5	12	21	**38**	6,903
Computer expenses	95	228	377	**700**	3,699
Office costs	123	294	487	**904**	3,970
Office rent	2,384	5,450	9,196	**17,030**	15,000
Advertising	3,625	8,668	14,347	**26,640**	4,320
Insurance	322	770	1,274	**2,366**	2,287
Audit and accountancy	454	1,085	1,797	**3,336**	3,702
Depreciation	488	1,116	1,883	**3,487**	3,258
Loss on disposal of fixed asset	21	51	85	**157**	-
	11,453	27,027	44,991	**83,471**	70,929

8. Net movement in funds

This is stated after charging:

	2017	2016
	£	£
Depreciation	**3,487**	3,258
Trustees' remuneration	**Nil**	Nil
Trustees' reimbursed expenses	**Nil**	574
Auditors' remuneration:		
▪ Statutory audit (including VAT)	**3,336**	3,702

Trustees' reimbursed expenses in 2016 represent payments made on behalf of 2 trustees for their travel and accommodation.

9. Staff costs and numbers

Staff costs were as follows:

	2017	2016
	£	£
Salaries and wages	**188,840**	180,546
Social security costs	**13,096**	13,122
Pension contributions	**5,450**	-
	207,386	193,668

No employee earned more than £60,000 during the year (2016: none).

The key management personnel of the charity comprise the trustees, the Chief Executive and the Chief Operating Officer. The total employee benefits received by the charity's key management personnel in the period was £79,382 (2016: £75,170).

	2017	2016
	No.	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.

11. Tangible fixed assets

	Total
	£
Cost	
At 1 April 2016	**22,619**
Additions in year	**1,614**
Disposals	**(314)**
At 31 March 2017	**23,919**
Depreciation	
At 1 April 2016	**13,910**
Charge for the year	**3,487**
On disposal	**(157)**
At 31 March 2017	**17,240**
Net book value	
At 31 March 2017	**6,679**
At 31 March 2016	8,709

12. Investments

	2017	2016
	£	£
Other investments - artwork	**700**	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 2017.

13. Stock

	2017	2016
	£	£
Merchandise	**1,711**	3,839

14. Debtors

	2017	2016
	£	£
Trade debtors	**265**	329
Prepayments	**7,673**	7,779
	7,938	8,108

15. Creditors : amounts due within 1 year

	2017	2016
	£	£
Trade creditors	**129**	4,279
Credit card	**194**	274
Accruals	**11,511**	4,099
Other taxation and social security	**4,214**	4,147
	16,048	12,799

16. Analysis of net assets between funds

	Restricted funds	Unrestricted funds	**Total funds**
	£	£	**£**
Tangible fixed assets	-	6,679	**6,679**
Investments	-	700	**700**
Net current assets	11,025	288,439	**299,464**
Net assets at 31 March 2017	**11,025**	**295,818**	**306,843**

17. Movements in funds

	At 1 April 2016 £	Income £	Expenditure £	Transfers between funds £	At 31 March 2017 £
Restricted funds					
Family support services	20,467	9,202	(20,019)	-	**9,650**
Information and awareness	-	5,971	(4,596)	-	**1,375**
Front end support	-	700	(700)	-	**-**
Total restricted funds	20,467	15,873	(25,315)	-	**11,025**
Unrestricted funds					
Designated funds:					
Listening Ear Fund	40,000	-	-	-	**40,000**
Total designated funds	40,000	-	-	-	**40,000**
General funds	278,132	309,245	(331,559)	-	**255,818**
Total unrestricted funds	318,132	309,245	(331,559)	-	**295,818**
Total funds	338,599	325,118	(356,874)	-	**306,843**

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 the Mary Homfray and Oakdale Trusts to support families and professionals in Wales, the Maximus Foundation and The Pilkington Trust for our planned North West Family Day, scheduled for June 2017 and from the Leathersellers Company and DM Thomas Foundation for a planned event in London to take place before March 2018.

Information and awareness
Funds received include grants from Hazelwood School, Oxted, David Solomons Charitable Trust and Wright Hassall Llp to enable us to continue to increase our library of published information guides to specific rare chromosome disorders and practical guides for families.

Front end support
We received a grant via a branch of the Chelsea Building Society in Surrey to purchase two printers to be used to support frontline services. These are used to print resources for new member families, including information guides and tailored responses relating to their child's rare chromosome or gene disorder.

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.

18. Related party transactions
There were no related party transactions during the financial year ended 31 March 2017 (2016: none).