Company no. 05460413
Charity no. 1110661

Rare Chromosome Disorder Support Group

Report and Audited Financial Statements

31 March 2016

Rare Chromosome Disorder Support Group

Contents

For the year ended 31 March 2016

Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2016

Company number	05460413
Charity number	1110661
Registered office	Valiant House 3 Grange Mills Weir Road London SW12 0NE
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:

Sophie Sainty	Chairman until September 2015, Trustee
Sally Cohen	Vice Chairman
Edna Knight, MBE	Founder, Life President
Helen Campbell	Trustee, Chairman from September 2015
Fiona de Zoete	Trustee
Isobel Hindle	Trustee
Gillian Manvell	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
Bankers	Charities Aid Foundation Kings Hill West Malling Kent ME19 4TA Lloyds PO Box 545 Faryners House 25 Monument Street London EC3R 8BQ

Auditors	Godfrey Wilson Ltd Chartered accountants and statutory auditors Zone 10 Bath Road Studios 470 Bath Road Bristol BS4 3HG

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2016

The trustees present their report and the audited financial statements for the year ended 31 March 2016.

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).

Every year we are amazed at the rate of growth in demand for the services we provide and 2015-16 was no exception. Almost 1,500 new families joined us compared to an average over the past 5 years of 1,136 families per annum. We are delighted to welcome those families affected by rare chromosome disorders and the life-long difficulties and disabilities that they may cause, but expansion results in us asking more of our staff, volunteers and trustees and I thank them for the dedication they show. We are also incredibly proud of, and grateful for, the people who fundraise for us. This year saw Unique's highest ever revenue at a time when grant funding is harder to obtain. Our members, their families, friends and colleagues have excelled this year in fundraising and voluntary donations.

In July 2015 we had the privilege to present the Unique Garden at the RHS Hampton Court Flower Show. The garden won a Silver medal from the RHS judges, but more importantly to us we won the People's Choice Award. The garden provided us with a beautiful setting to meet 1,000's of people over 6 days; some were our members, able to meet the staff amongst the agapanthus and lavenders and to rest awhile for a chat, but many more were people hearing about Unique and rare chromosome disorders for the first time. The awareness-raising opportunity was fantastic and was topped by a piece on the BBC at prime time. The garden was produced on a shoestring budget of £10,000, mainly crowd funded by our members.

We continued to expand production of our authoritative guides and now have 180 in the library available for download from our site by both families and medical professionals globally. These guides are produced by our scientifically-qualified team of information officers and this year we added our first guides to specific single gene disorders, as well as increasing our generic practical guides. It is often these guides which are the first information families have post diagnosis and we know from feedback that those families find them crucial.

We offered three regional family days during the year. These were in Exeter (South West), Harrogate (Yorkshire) and Newport (South Wales). Family days are one of the most important services we provide, they give families an opportunity to meet up, and by sharing challenges and successes, to support each other. They also give the families access to both clinical and lab-based geneticists, an opportunity many rarely get but often appreciate.

We held our second Rare Chromosome Disorder Awareness Week, which saw our members again taking to social media with a relish. We had 'selfie Sunday', daily facts and story sharing. In schools, workplaces and at home bake sales were held, craft was made and more stories were shared.

We know that the greatest asset we have in awareness and fundraising is our members and their enthusiasm to support each other and to educate others on the joys and challenges of having a child with a rare chromosome disorder. Thank you to all our members, for the support you give us and more importantly for the support you provide each other.

Helen Campbell, Chair of Trustees July 2016

Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2016

Background: Rare Chromosome and Genomic Disorders

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

Advances in the technology used to diagnose RCDs mean that many more people than ever before are receiving a diagnosis. Despite this, there remains a lack of knowledge and understanding about these conditions among many doctors and other health professionals. As parents struggle with a complex diagnosis for their child, they have lots of questions but many go unanswered, exacerbating their all-too-real feelings of distress, isolation and worries for the future. This is where Unique can and does help.

Aims and Objectives

Our aims and objectives 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.

Unique provides specialist information and support to the parents and carers of those affected. We aim to help them come to terms with their child's diagnosis, better understand it, and then face the future with renewed hope. We have built strong working relationships with large numbers of medical and other professionals, with many now signposting 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: Support and Information

Having received a diagnosis of a Rare Chromosome Disorder for their child, parents need clear, easy to understand information to help them come to terms with it. They need to have complex terminology explained and a majority also need softer support – someone to listen and empathise. Accordingly, Family Support and Specialist Information form the bedrock of the service we provide.

Our **Family Support services** include:

- **The *Unique* Listening Ear:** our telephone and email helpline is often the first point of contact for distressed parents of a newly-diagnosed child. Staffed by an experienced team, able to empathise with parents and clearly explain complex terminology to help them understand their child's diagnosis. The service is also used by medical and other professionals in need of information to help them counsel patients, monitor for conditions associated with a particular RCD and plan care.

- ***Unique's*** **Family matching service:** we link those living with similar conditions or facing similar challenges. Bringing families together in this way offers invaluable mutual support, "lightening the darkness" as one parent put it.
- **Regional and National Events for families:** these include Unique family days, disorder-specific study days and family conference weekends. Families can meet and get to know others in a similar position and develop ongoing, informal support networks. These events also help to further our knowledge of specific RCDs and help those affected and their families to access the help and support they need.
- **Networking:** we have set up and run very active social media groups which are a hit with families who tell us they are a lifeline. They are safe environments where staff, trustees and other families offer tips, information, guidance and support to those in need.

Provision of **Specialist Information** includes:

- **The *Unique* information project:** we have now produced over 180 guides to specific rare chromosome and single gene disorders, a library of resources unique of its type. The guides are written in accessible, family-friendly language, based largely on evidence provided by Unique member families and data gleaned from the often limited published medical literature. All guides are independently verified prior to publication by medical and other professionals who volunteer their time and are available free of charge from our website or from Unique staff. We also have 11 'practical guides' for families on more general but highly relevant topic such as communication, education, dental issues and sleep problems.
- **The *Unique* database/patient registry:** data collected from Unique member families forms the basis for our information guides and is at the heart of the services we provide to those who need our help. It contains behavioural, social, educational and developmental information so goes way beyond purely medical data. We use it 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:** HonCode accredited ('Health on the Net' Code) and full of regularly updated information and resources.
- **The Unique magazine:** published three times per year and highly valued by Unique families, many of whom contribute their own updates to help others. Each edition has lots of articles of interest, tips, resources and fundraising ideas.
- Our **network of over 200 local volunteer contacts,** helping us support families in their area, using invaluable local knowledge to signpost them to local services and resources.

Vision and Mission Statement: Unique's core values

Vision

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

Mission Statement

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

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 and objectives, planning future strategy and setting policy.

In terms of the wider benefits to society that Unique provides, we have actively supported the use 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. The genomics knowledge and expertise gained has the huge potential to benefit more mainstream areas of medicine, e.g. cardiology and respiratory medicine and to deliver personalised medicine.

The following section details some examples of our activities and achievements during the year, undertaken to further the charity's purpose for the public benefit.

Activities and Achievements during 2015-16

During the year we continued to see increasingly high levels of demand for our services. Just under 1,500 new member families joined us, representing a huge increase of 30% on the average number of new members for the five years prior to 2015-16. Total membership at the end of March 2016 stood at over 13,700 families, representing well over 15,000 individuals affected by a RCD.

Advances in diagnostic technology, coupled with professionals referring families to Unique and our own awareness-raising activities have all contributed to this rising demand. Our frontline services are therefore under real pressure but Trustees have again been impressed with the dedication, professionalism and commitment of the staff team in helping all those who need us. Below are our key achievements during the year, broken down into each major strand of our service:

1. The Unique Information project:

- Information guides are produced by our two part-time Information Officers who during the year produced 17 new information guides to specific RCDs, including a tranche of guides to new, single gene disorders – the very first such resource of their kind. We now have more than 180 information guides, a resource no other organisation offers.
- We are acutely aware of the need for information to be kept up to date and in addition to the newly published guides, 5 existing information guides were substantially updated. This is only made possible by member families providing updated data about their affected children and adults. Many of our members are now reaching adulthood, hence the need to collect lifetime data which is in turn used directly to help many other families.
- Unique members and professional supporters speak a variety of languages and in response, lots of our information guides have been translated into languages including Arabic, Polish, French, German, Greek, Spanish and Russian. This year 15 more guides were translated into various foreign languages as demand increases from those for whom English is not their mother tongue. Translation is undertaken entirely by volunteers and we are extremely grateful for their time.
- Dr Anna Pelling who has a background as a Research Scientist and worked with us on a project in collaboration with Oxford University and the Nuffield Foundation, was recruited to a part-time role as an Information Officer to write and publish information guides.

The information guides are available free of charge through our website: www.rarechromo.org. We want to ensure full access and that nobody is dissuaded from using our information on financial grounds.

2. Family Support services

- Our Listening Ear team had another busy and challenging year, answering more than 9,300 telephone and email queries from families, plus a further 1,800 from medical and other professionals. All were provided with information and support that is not available elsewhere.
- During the year we recruited our first full-time Information Officer, having previously only been able to employ part-time Information Officers. Arti Patel previously worked for a large disability charity and has been of huge benefit to Unique families, bringing relevant professional and personal experience and further increasing our capacity to respond to their needs.
- Updating the database entries for all members continued 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 continued to use her vast knowledge and experience of chromosome disorders and the wider disability sector to establish what families' immediate needs are and signpost them to appropriate resources. She also monitors our social media networks which provide a safe environment for families to meet others, swap tips, share resources, ask questions and provide informal, mutual support.
- We continued to provide our 'Unique awareness card' to parents and carers to explain their child's condition. Hundreds more were given out this year and used in restaurants and when queuing in shops, explaining the child's condition and why they may have difficult queuing.
- The Unique website has a variety of resources for families. It is updated regularly and also helps professionals counselling patients. We continued to benefit from a Google grant, increasing the charity's online visibility, making it easier for those in need to find and access our services.

3. Networks for Families and Professionals

> *"When you're with people who just 'get it', it's so good. Our children may not have the same issues but when people understand, it's great!"*
>
> *"It was great to chat to meet some lovely and like-minded people. I also got to speak to a geneticist which was really good as trying to get an appointment with them can be very tricky."*

- This year we ran three more in our successful series of regional family days across the UK, with events in the South West, Yorkshire and South Wales. The events bring families together to relax and meet others in a supportive, non-judgmental environment. Informal in nature, families have lunch and children's entertainment, face painting and soft play are provided. Each event was attended by over 70 adults and 50 children together with laboratory-based geneticists from local regional genetics centres who gave demonstrations about genetic testing and answered questions from parents. Further events in Scotland, Northern Ireland and London are planned for 2016-17. The medium to longer-term aim is that by meeting face to face, local families (supported by Unique local volunteer contacts) will go on to form lasting support networks.
- We are hugely grateful to the many lab-based geneticists, Consultant Clinical Geneticists and other professionals who gave up their time to attend our events. This is testimony to our strong relationships with specialists in hospitals and Regional Genetics Centres across the UK.
- Our post-moderated social media groups including our secret Facebook 'Cafe', have thousands of members and have become a lifeline for many, who now feel part of a wider community having previous been isolated. Staff often answer questions or provide information when members ask a question. This has proved to be an effective way of working, helping to relieve pressure from frontline services such as our Listening Ear helpline.

- We continued to work closely with other third sector organisations. Unique's CEO Dr Searle sits on the Rare Disease UK Patient Empowerment Group, we are very active members of Genetic Alliance UK and we have close links with organisations such as Contact a Family and Genetic Disorders UK.
- The Unique Facebook 'Cafe', a secret group which provides a safe, supportive, online environment for families to discuss topics of relevance, swap tips and information reached the milestone of 4,000 members. This, together with lots of local groups, is a key part of the Unique network and families tell us it is a lifeline to them.
- Our regular email news bulletins reach thousands of members and supporters with news, fundraising ideas and details of events. We have over 4,000 Twitter followers. All these mean families are part of a wider public network, helping them overcome their feelings of isolation.

4. Awareness-Raising and Collaboration

The rarity of individual RCDs makes raising awareness among professionals and the wider community a key objective. Highlights this year included:

- The second global Rare Chromosome Disorder Awareness Week in June 2015, working closely with Chromosome Disorder Outreach in the US, to raise awareness about rare chromosome disorders and the daily challenges they bring.
- Our hugely successful, silver medal-winning 'show garden' at the RHS Hampton Court Palace Flower Show in July. Designed and built by designers & gardeners giving their time for free and produced on a relative shoestring, it was made possible by a crowd-funding appeal to our members and supporters. The garden meant the charity was exposed to an audience of 150,000 visitors and seen by millions of BBC TV viewers as it was featured on the highlights show with Monty Don presenting a piece from the Unique garden.
- Being nominated by the general public and then winning the Eurordis European Patient Organisation of the Year Award, 2016. This prestigious award recognised the services we provide to all those families living with and struggling to come to terms with a diagnosis of a RCD.
- Our CEO, Dr. Searle being invited by Professor Sue Hill, NHS England's Chief Scientific Officer, to sit on the NHS England 100,000 Genomics Project Programme board as Patient Representative.
- Being a member of the Rare Disease UK Patient Empowerment Group – working to implement the 51 commitments made in the UK Rare Disease Strategy.
- Unique patron Baroness Pauline Neville-Jones becoming a vice chair of the new All Party Parliamentary Group on Rare, Genetic and Undiagnosed Disorders.
- Having a very busy and successful awareness-raising stand at the joint ESHG/BSGM conference in Glasgow, attended by many thousands of geneticists from across the world.
- Dr. Searle presenting on the Genomics of Rare Disease at the Wellcome Trust Sanger Institute, to parents and professionals at a Cerebra conference and to the joint ClinGen/Decipher meeting in Washington. She has also continued to give teaching sessions to 2nd year medical students at University College, London, educating them about living with rare chromosome disorders.

Infrastructure

During the year, Trustees took the decision to invest in our first IT network. This has allowed more efficient and even more secure working with real-time, hierarchical access to the DB for relevant staff in our office or working remotely, as well as better management of personal data.

Challenges

As demand continues to increase rapidly and with limited resources, the challenge remains how we can best develop the charity's capacity to respond to the needs of all those affected by RCDs. Mindful of the ongoing uncertain climate for charities, we continued to invest in fundraising during the year, with diverse income streams to avoid an over-reliance on one particular strand. By doing so Trustees aim to minimise risk and ensure Unique's long-term sustainability. Our Chief Operating Officer is a member of the Institute of Fundraising and is also focused on building and developing the charity's infrastructure to be as robust as possible. In May 2014 we employed our first dedicated Fundraising Officer who continued to develop the role this year, supporting volunteer fundraisers, freshening our marketing and seeking to broaden our appeal to potential fundraisers and funders.

Towards the end of the year we began the process of recruiting another Information Officer to support families on our Listening Ear helpline. Safeguarding and building key services is paramount to remaining viable and sustainable to ensure we are there to help families when they most need us.

Volunteers

We are hugely grateful to a large number of people who gave up their time to help us, including:

- Over 200 Unique members volunteering as local contacts, offering support to other members in their area, signposting to local resources and being on hand as a sounding board or shoulder to cry on.
- Over 30 geneticists, medical and other professionals checking and verifying our information guides prior to publication, plus many more attending our family events.
- Volunteers translating our information guides into a variety of different languages.
- A number of others assisting with IT, marketing and promotional activities and despatching merchandise such as t-shirts, wristbands and Christmas cards.
- This year, for the first time, working with a short-term volunteer intern (to whom we paid an honorarium). She was a second year Biomedical Science student so benefitted greatly from working with us, learning about chromosome disorders and their effects to complement her studies, while Unique benefitted from her enthusiasm and hard work. We plan to repeat this with another student during 2016-17.
- Many hundreds more of our members, their friends and family and other supporters quite literally going the extra mile to raise the funds we need to provide our services.

Financial Review 2015-16

Income

Unique's income for the year is £373,721, representing an 18% increase on the previous year. Our unrestricted income from donations and fundraising from members and supporters, corporate, trusts and foundations totalled £318,837. Our proportion of unrestricted income being relatively high means that Trustees are able to direct funds to where they are most needed and in line with our strategic direction. It also means we are better able to plan for the future and are not reliant on third party organisations for funding, much of which can be for a fixed-term. From charitable trusts and foundations we received restricted income of £33,749. 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 £326,744, an increase of 6%. However, it was within the budget we set at the beginning of the year by 5.1%. 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 £4,321. Throughout the year we continued 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 2016-17 of not less than £100,000.

Mindful of ongoing economic uncertainty and the negative press surrounding the charity sector, during the year we continued to budget prudently, carefully controlling our expenditure. Reserves at the end of the year are at £338,599, with unrestricted reserves standing at £318,132. We are able to safeguard key services for our members and ensure the longer-term sustainability of Unique. Trustees have once again decided to designate £40,000 to protect the Listening Ear Telephone and Email helpline service. Some income received during 2015-16, e.g. grants received towards regional family days and other work to benefit Unique members has been carried forward to 2016-17 when the Regional Family Days will take place.

Strategic Direction and Plans for the Future
In the fast-moving and ever-changing worlds of genomics, health and disability, Trustees and senior staff constantly review the charity's strategic direction and at the time of writing have begun drafting ideas for the next 5-year operating plan. These will be formalised during the early part of 2016-17.

As more and more people receive diagnoses and approach us for help, our focus is on the continued development of the key services described above, as well as strengthening our infrastructure. To ensure the charity is best able to meet the needs of beneficiaries, key areas for development include:

- Strengthening our information and family support services to build our capacity to respond to the families who need us.
- Ramping up our awareness-raising activities, including building on the successes of Chromosome Disorder Awareness Week.
- Running more events to bring families and professionals together – combating families' feelings of isolation and developing awareness and understanding of rare chromosome and genomic disorders.
- Continuing to strengthen our fundraising efforts to support our objectives and build on the successes of the past couple of years.
- Updating the information contained within and further development of our specialist database/patient registry.

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 Northern Ireland, the East Midlands and London as we continue this series of events across all areas of the UK.
- Adding further information guides to our library of resources, including an expansion of the new series of guides to single gene disorders. We will also continue to expand our range of practical guides for families, covering more general topics.
- Continuing to invest in staffing resources to strengthen the charity's capacity to respond to and help all those who need us. Recruitment of a part-time Information Officer is planned for midway through 2016-17.
- Working with other organisations across the world on the third annual Rare Chromosome Disorder Awareness week, planned for June 2017.

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 rare chromosome disorder. This will coincide with the completion of our project to convert all historic paper records of patient information to scanned, electronic copies, saving staff time in searching for data and the cost of storage.

Structure, Governance and Management

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

Corporate and Social Responsibility and Sustainability

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 and regularly communicated via VOIP to minimise costs and our carbon footprint. Two other staff split their working hours between home and office working.

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 referred to 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 three 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 during which training needs are identified and training sourced where appropriate. Various staff underwent training during the year, including two members of staff completing a massive open online course (MOOC) on the Future of Genetics in Medicine provided St George's, University of London.

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. In addition to the three board meetings per year, Trustees hold monthly Skype/teleconference meetings with key staff with the focus primarily on financial performance. 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, 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 October 2015 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 8 September 2016 and signed on their behalf by

Edna Knight - Trustee (Life President)

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 2016 which comprise the statement of financial activities, balance sheet 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 2016 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.

Date: 8 September 2016

Alison Godfrey FCA
(Senior Statutory Auditor)
For and on behalf of:

GODFREY WILSON LIMITED
Chartered accountants and statutory auditors
Zone 10 Bath Road Studios
470 Bath Road
Bristol
BS4 3HG

Rare Chromosome Disorder Support Group

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

For the year ended 31 March 2016

	Note	Restricted £	Unrestricted £	**2016 Total £**	Restated 2015 Total £
Income from:					
Donations and legacies	3	7,217	318,837	**326,054**	244,248
Charitable activities:					
Family support services	4	22,825	-	**22,825**	40,750
Information and awareness	5	10,924	10,528	**21,452**	27,834
Investments		-	3,390	**3,390**	3,521
Total income		40,966	332,755	**373,721**	316,353
Expenditure on:					
Raising funds		-	67,328	**67,328**	62,710
Charitable activities:					
Family support services		11,925	142,066	**153,991**	154,143
Information and awareness		22,628	82,797	**105,425**	90,139
Total expenditure	6	34,553	292,191	**326,744**	306,992
Net income		6,413	40,564	**46,977**	9,361
Transfers between funds		-	-	**-**	-
Net movement in funds	8	6,413	40,564	**46,977**	9,361
Reconciliation of funds					
Total funds brought forward		14,054	277,568	**291,622**	282,261
Total funds carried forward		20,467	318,132	**338,599**	291,622

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.

The 2015 comparatives have been restated in line with the Charities SORP (FRS 102). The restatements are purely reclassifications of income and expenditure and do not affect net income.

Rare Chromosome Disorder Support Group

Balance sheet

As at 31 March 2016

	Note	£	2016 £	2015 £
Fixed assets				
Tangible fixed assets	11		**8,709**	3,587
Investments	12		**700**	700
			9,409	4,287
Current assets				
Stock	13	**3,839**		1,517
Debtors: amounts due within 1 year	14	**8,108**		9,545
Debtors: amounts due after 1 year	14	**-**		749
Current asset investments		**55,605**		55,000
Cash at bank and in hand		**274,437**		245,043
		341,989		311,854
Creditors: amounts due within 1 year	15	**12,799**		24,519
Net current assets			**329,190**	287,335
Net assets	16		**338,599**	291,622
Funds	17			
Restricted income funds			**20,467**	14,054
Unrestricted funds:				
Designated funds			**40,000**	40,000
General funds			**278,132**	237,568
Total charity funds			**338,599**	291,622

Approved by the trustees on 8 September 2016 and signed on their behalf by

Edna Knight - Trustee (Life President) Helen Campbell - Trustee (Chair)

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).

The charity has chosen to early adopt the Charities SORP (FRS 102) Update Bulletin 1 in preparing these financial statements, and have taken advantage of the exemption from preparing a cash flow statement.

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 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	20%
Family support services	48%
Information and awareness	32%

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) Transition to FRS 102
No restatement of the opening fund position was required in making the transition to FRS 102. The transition date was 1 April 2014.

2. Prior period comparatives

	Restricted £	Unrestricted £	2015 Total £
Income from:			
Donations and legacies	6,294	237,954	**244,248**
Charitable activities			
Family support services	37,080	3,670	**40,750**
Information and awareness	17,624	10,210	**27,834**
Investments	-	3,521	**3,521**
Total income	60,998	255,355	**316,353**
Expenditure on:			
Raising funds	-	62,710	**62,710**
Charitable activities			
Family support services	39,466	114,677	**154,143**
Information and awareness	18,983	71,156	**90,139**
Total expenditure	58,449	248,543	**306,992**
Net income	2,549	6,812	**9,361**
Transfers between funds	-	-	**-**
Net movement in funds	2,549	6,812	**9,361**

3. Donations and legacies

	Restricted £	Unrestricted £	**2016 Total £**	2015 Total £
Grants > £5,000:				
D & J Hunter Charitable Trust	-	10,000	**10,000**	10,000
Grants from individuals	-	10,000	**10,000**	-
Grants < £5,000	-	3,000	**3,000**	6,780
Donated goods / services *		4,321	**4,321**	4,498
General donations	5,037	86,677	**91,714**	64,469
Corporate donations	746	21,441	**22,187**	22,947
Overseas donations	38	13,720	**13,758**	10,223
Gift aid	-	29,330	**29,330**	26,597
Give As You Earn (GAYE)	-	946	**946**	1,680
Pyramids	-	482	**482**	808
Legacy	-	-	**-**	1,000
Donations from fundraising activities	1,396	138,920	**140,316**	95,246
Total donations and legacies	7,217	318,837	**326,054**	244,248

* Donated services consist of the following:

	2016 £	2015 £
Google AdWords (free web advertising)	**4,321**	3,748
Freelance designer	**-**	750
Total donated services	**4,321**	4,498

4. Charitable activities: family support services

	Restricted £	Unrestricted £	**2016 Total £**	2015 Total £
Grants > £5,000:				
Jeans for Genes	6,000	-	**6,000**	25,000
Big Lottery Fund Grant	5,825	-	**5,825**	-
DM Thomas Foundation for Young People	5,000	-	**5,000**	-
Grants < £5,000	6,000	-	**6,000**	12,080
Conference income	-	-	**-**	3,670
Total family support services	22,825	-	**22,825**	40,750

5. Charitable activities: information and awareness

	Restricted £	Unrestricted £	**2016 Total £**	2015 Total £
Grants > £5,000:				
Oxford University	10,653	-	**10,653**	-
Grants < £5,000	271	-	**271**	17,068
Christmas card and merchandise sales	-	10,528	**10,528**	10,210
Other income	-	-	**-**	556
Total information and awareness	10,924	10,528	**21,452**	27,834

6. Total expenditure

	Raising funds £	Family support £	Information and awareness £	**2016 Total £**	2015 Total £
Staff costs (note 9)	37,633	90,579	65,456	**193,668**	186,956
Training and other staff costs	328	214	104	**646**	615
Postage and distribution *	4,981	21,285	4,801	**31,067**	17,352
Printing and design	70	12,736	2,660	**15,466**	19,053
Stationery	377	963	803	**2,143**	3,154
Subscriptions, licences and charges	11,572	371	3,007	**14,950**	13,630
Travel and subsistence	165	2,333	2,322	**4,820**	8,896
Room hire and event costs	1,381	6,192	13,288	**20,861**	22,113
Computer expenses	4,314	2,417	1,184	**7,915**	4,999
Office costs	794	3,067	2,042	**5,903**	4,877
Office rent	3,000	7,200	4,800	**15,000**	15,000
Website and database development	-	121	-	**121**	236
Advertising **	864	2,074	1,999	**4,937**	3,748
Insurance	457	1,098	732	**2,287**	2,149
Audit and accountancy	740	1,777	1,185	**3,702**	3,240
Depreciation	652	1,564	1,042	**3,258**	974
Total expenditure	67,328	153,991	105,425	**326,744**	306,992

* We usually post out three editions of our members' magazine per year but the March 2015 edition was sent out later than planned, in April. This means the costs associated with four editions of the magazine are included in these accounts (2015-16), rather than the usual three, creating a temporary spike in postal costs. Only two editions were sent out during 2014-15, artificially lowering that year's expenditure. The total number of new members for the year is around 30% higher than the average for the 5 years prior, also increasing postal costs.

** 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	**2016 Total**	2015 Total Restated
	£	£	£	**£**	£
Staff costs	4,201	10,083	6,722	**21,006**	23,005
Training and other staff costs	65	155	104	**324**	-
Postage and distribution	808	1,941	1,294	**4,043**	239
Printing and design	-	-	-	**-**	53
Stationery	353	846	564	**1,763**	307
Subscriptions, licences and charges	42	102	68	**212**	709
Travel and subsistence	88	212	142	**442**	258
Room hire and event costs	1,381	3,313	2,209	**6,903**	29
Computer expenses	740	1,775	1,184	**3,699**	138
Office costs	794	1,906	1,270	**3,970**	718
Office rent	3,000	7,200	4,800	**15,000**	15,000
Advertising	864	2,074	1,382	**4,320**	3,748
Insurance	457	1,098	732	**2,287**	2,149
Audit and accountancy	740	1,777	1,185	**3,702**	3,240
Depreciation	652	1,564	1,042	**3,258**	974
	14,185	34,046	22,698	**70,929**	50,567

Restated comparatives for 2015 include support and governance costs as per SORP 2015 requirements.

8. Net movement in funds

This is stated after charging:

	2016	2015
	£	£
Depreciation	**3,258**	974
Trustees' remuneration	**Nil**	Nil
Trustees' reimbursed expenses	**574**	Nil
Auditors' remuneration:		
▪ Statutory audit (including VAT)	**3,702**	3,240

Trustees' reimbursed expenses represent payments made on behalf of two trustees (2015: none) for their travel and accommodation.

9. Staff costs and numbers

Staff costs were as follows:

	2016	2015
	£	£
Salaries and wages	**180,546**	172,656
Social security costs	**13,122**	12,507
Freelance staff	**-**	1,793
	193,668	186,956

No employee earned more than £60,000 during the year (2015: 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 £75,170 (2015: £73,696).

	2016	2015
	No.	No.
Average staff head count	**9.00**	9.00
Average full time equivalent	**6.00**	5.80

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 2015	**14,239**
Additions in year	**8,380**
At 31 March 2016	**22,619**
Depreciation	
At 1 April 2015	**10,652**
Charge for the year	**3,258**
At 31 March 2016	**13,910**
Net book value	
At 31 March 2016	**8,709**
At 31 March 2015	3,587

12. Investments

	2016 **£**	2015 £
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 2016.

13. Stock

	2016 **£**	2015 £
Merchandise	**3,839**	1,517

14. Debtors

	2016	2015
	£	£
Amounts due within 1 year:		
Trade debtors	**329**	1,478
Prepayments	**7,779**	8,067
	8,108	9,545
Amounts due after 1 year:		
Accrued income	**-**	749

15. Creditors : amounts due within 1 year

	2016	2015
	£	£
Trade creditors	**4,279**	1,636
Credit card	**274**	3,128
Accruals	**4,099**	5,762
Other taxation and social security	**4,147**	3,340
Deferred income	**-**	10,653
	12,799	24,519

Movements in deferred income consist of:

	2016	2015
	£	£
Balance at the start of the year	**10,653**	25,000
Increase / (decrease) in income in advance	**(10,653)**	(14,347)
Balance at the end of the year	**-**	10,653

The charity occassionally receives income in advance of the provision of services. Where this relates to future periods, the income is deferred.

16. Analysis of net assets between funds

	Restricted funds	Unrestricted funds	**Total funds**
	£	£	**£**
Tangible fixed assets	-	8,709	**8,709**
Investments	-	700	**700**
Current assets	20,667	321,322	**341,989**
Current liabilities	(200)	(12,599)	**(12,799)**
Net assets at 31 March 2016	**20,467**	**318,132**	**338,599**

17. Movements in funds

	At 1 April 2015 £	Income £	Expenditure £	Transfers between funds £	**At 31 March 2016 £**
Restricted funds					
Family support services	7,425	24,967	(11,925)	-	**20,467**
Information and awareness	6,629	15,999	(22,628)	-	**-**
Total restricted funds	14,054	40,966	(34,553)	-	**20,467**
Unrestricted funds					
Designated funds:					
Listening Ear Fund	40,000	-	-	-	**40,000**
Total designated funds	40,000	-	-	-	**40,000**
General funds	237,568	332,755	(292,191)	-	**278,132**
Total unrestricted funds	277,568	332,755	(292,191)	-	**318,132**
Total funds	291,622	373,721	(326,744)	-	**338,599**

Purposes of restricted funds

Family support services

This is funding for our frontline services to families to continue throughout 2016-17, including our Listening Ear telephone and email helpline, the first point of contact for parents who have received a diagnosis of a rare chromosome disorder for their child. The funds include grants received from the Simon Gibson Charitable trust and the Cornwell Charitable Trust. Also included is a grant from the DM Thomas Foundation for Young People to run two one-day family days for Unique member families in Northern Ireland and London. These are scheduled to take place in March 2017.

Information and awareness

Funds received, including a further grant from the DM Thomas Foundation for Young People, to enable us to continue to continue to increase our library of published information guides to specific rare chromosome disorders during the coming year.

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 2016 (2015: none).