

Company no. 05460413  
Charity no. 1110661

**Rare Chromosome Disorder Support  
Group**

**Report and Audited Financial Statements**

**31 March 2018**

## Rare Chromosome Disorder Support Group

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**For the year ended 31 March 2018**

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## Rare Chromosome Disorder Support Group

### Reference and administrative details

**For the year ended 31 March 2018**

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<b>Company number</b>	05460413
<b>Charity number</b>	1110661
<b>Registered office</b>	Valiant House 3 Grange Mills Weir Road London SW12 0NE
<b>Operational address</b>	The Stables Station Road West Oxted Surrey RH8 9EE
<b>Trustees</b>	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, Trustee Edna Knight, MBE                      Founder, Life President, Trustee Fiona de Zoete                          Trustee Isobel Hindle                              Trustee Gillian Manvell                          Trustee Sophie Sainty                              Trustee Benjamin Stern                           Trustee James Toop                                Trustee (appointed 6 October 2017)
<b>Chief executive officer</b>	Beverly Searle, PhD
<b>Company secretary</b>	Craig Mitchell MInstF (Dip)
<b>Patrons</b>	Professor Dian Donnai, UK Professor Jean-Pierre Fryns, Belgium Professor Judith Hall, Canada Baroness Pauline Neville-Jones, UK Professor Albert Schinzel, Switzerland

## Rare Chromosome Disorder Support Group

### Reference and administrative details

For the year ended 31 March 2018

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#### Bankers

Charities Aid Foundation  
Kings Hill  
West Malling  
Kent  
ME19 4TA

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

United Trust Bank  
1 Ropemaker Street  
London  
EC2Y 9AW

Yorkshire Building Society  
Yorkshire House, Yorkshire Drive  
Bradford  
BD5 8LJ

Virgin Money plc  
Jubilee House  
Gosforth  
Newcastle-upon-Tyne  
NE3 4PL

#### Auditors

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

## **Rare Chromosome Disorder Support Group**

### **Report of the trustees**

#### **For the year ended 31 March 2018**

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The trustees present their report and the audited financial statements for the year ended 31 March 2018.

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 year was a challenging one financially for Unique. Like many small charities we saw our revenue decline and we were required to look for cost savings whilst not impacting the quality of our service provision. The Charities Aid Foundation reported that total charitable giving in the UK increased in the period but that the number of people donating declined, led by a decline in sponsorship. This trend is worrying news for Unique and means we need to continue our efforts to find alternative sources of revenue, such as overseas donations and legacies.

The Trustees continued to budget prudently to ensure longer-term sustainability and were able to reduce expenditure without having to cut services or staff. As demand for our services continued to increase, staff responded with professionalism and dedication to help all those who needed us throughout the year.

At the close of the year we launched a new Unique website. Many months of development were undertaken and we now have a site which is fully mobile-responsive and more easily navigable. Since launching the website, we have seen an immediate and ongoing uplift in numbers of new families joining us and therefore accessing the help and support they need.

During the year we welcomed James Toop who joined us as a Trustee. His extensive IT background helps meet our strategic aim of upgrading the charity's digital capabilities and strengthening our IT infrastructure and data security. I am proud to lead a board of nine trustees with a diverse range of skills but a common passion for the work of Unique. This passion was borne out when it was realised that the new General Data Protection Regulation (GDPR) in the UK could result in the entire Unique database needing to be deleted. Sophie Sainty, a trustee, shared her concerns with Baroness Neville-Jones, our patron, whose advice was to just 'simply' get the law changed. Together with Genetic Alliance UK, Sophie and Baroness Neville-Jones, along with senior members of Unique staff, did just that – they worked on an amendment which has now been ratified in parliament having received cross-party support. We are extremely proud of and extremely grateful to them.

Helen Campbell, Chair of Trustees, July 2018.

## Rare Chromosome Disorder Support Group

### Report of the trustees

For the year ended 31 March 2018

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#### Unique's Mission

To inform, support and to create networks to alleviate the isolation of anyone affected by a rare chromosome or gene disorder (RCD) 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.

#### 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. Often causing severe learning and physical disabilities, there is currently no cure. Although they are individually rare (some literally unique), collectively they affect at least 1 in 200 live-born babies, many of whom 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.

With huge advances in diagnostic technology, many more people are now receiving a diagnosis of a RCD. However, the rarity of individual conditions means there remains a lack of knowledge and understanding about them among many doctors and other health professionals. Parents receive a complex diagnosis for their child and inevitably have lots of questions but many go unanswered, causing real distress and feelings of isolation. This is where Unique comes in.

#### How we Help: Support, Information and Networking

Unique provides specialist information and support to the parents and carers of those with RCDs, to help them understand their child's diagnosis and begin to come to terms with it. We also work to raise awareness of the disorders among health and other professionals and the wider public. Only through greater awareness can we foster increased understanding of the daily challenges faced by those affected and their families, along with improved care.

As parents often struggle to understand their child's condition, they need someone to explain complex terminology in an understandable way and to outline what the future might hold. Family Support and Specialist Information are therefore key strands of our services, which include:

- **The Unique Listening Ear** telephone and email helpline, often the first point of contact for distressed parents of a newly-diagnosed child. Our experienced staff empathise with parents and answer their many questions. Medical and other professionals also contact us for help when counselling patients and planning care.
- **Unique's Family matching service**, linking those living with similar conditions or facing similar challenges.
- **The Unique Information Project**, which through careful research using evidence gathered from families and the often limited published medical literature as well as help from experts in the field produces family-friendly, medically verified information guides for families. These are often the only source of information families have about their child's RCD at the time of diagnosis.
- **Family Events**, e.g. regional family days and disorder-specific study days, bringing families together to meet others and develop mutual support networks. Expert professionals also attend, furthering our knowledge of RCDs and helping families access information and other resources.

## Rare Chromosome Disorder Support Group

### Report of the trustees

#### For the year ended 31 March 2018

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- The **Unique database/patient registry**, containing rich data provided by member families. As well as purely medical data, it includes behavioural, social, educational and developmental information and is used anonymously to inform researchers, geneticists and other professionals and by our staff to guide families on their child's condition.
- Our active **Social Networks**, which are safe, supportive, moderated environments for families to swap tips, share information and offer support.
- Our website, **www.rarechromo.org** which is full of information and resources and is used by families to join us via an online form.
- The **Unique magazine**, containing articles submitted by families, resources, research studies, awareness-raising and fundraising ideas. We publish 2-3 editions per year.
- 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.

#### 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 specialist information as well as softer support.

For the wider public benefit, we have actively supported the development of next generation DNA sequencing and streamlining of the genetics and genomics service in the UK to provide families with a diagnosis of a rare disease. This is most notably through the 100,000 Genomes project. During the year, Dr. Searle sat on NHS England's Rare Disease Transition Working Group, looking at how best to implement genomics across the healthcare system and on the Department of Health's Rare Disease Policy Board. This focuses on national and UK level policy development and implementation of the 51 commitments in the UK strategy for rare diseases. The genomics and rare disease expertise gained has huge potential to benefit more mainstream areas of medicine, e.g. cardiology and respiratory medicine and to deliver personalised medicine.

#### Activities and Achievements During 2017-18

The following is a summary of our key achievements during the year in the furtherance of our charitable aims and objectives.

#### Working Towards Changing the Law to Help UK Patient Support

In preparing for the General Data Protection Regulation (GDPR), to be implemented in May 2018, it became apparent that there was a risk that we could be required to delete huge amounts of valuable data, given willingly by our member families. We felt that seeking regular renewed consent from families caring for disabled children, with the huge challenges and burdens that entails, was unrealistic. Working with Unique patron Baroness Pauline Neville-Jones, our Trustee Sophie Sainty and the team at Genetic Alliance UK, we secured government agreement to an amendment to the law. This means that patient support groups working with certain types of historical health data which they had consent to process under the previous regulations, will not be required to refresh consents to process such data. At the time of writing, the amendment has government agreement and is subject to ratification of the Data Protection Bill in parliament.

## Rare Chromosome Disorder Support Group

### Report of the trustees

#### For the year ended 31 March 2018

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##### **Rapid Growth in Demand Continues**

Between April 2017 and March 2018, 1,493 new member families joined us, an increase of 8% on our 5-year average, taking total membership at the end of March 2018 to over 16,500 families. This represents well over 18,500 individuals with a RCD.

It is crucial that families can easily find the help and support they need. Many families are referred to us by healthcare and other professionals who value our work highly and tell them about us as a first point of contact. Others find us as a result of our proactive marketing efforts, including our active social media presence and continued Google grant, helping to improve our online visibility.

In March 2018, following many months in development, we launched a brand new, fully mobile-responsive Unique website at [www.rarechromo.org](http://www.rarechromo.org). This easier accessibility led to an immediate large increase in the numbers of new families approaching us for help and March 2018 became the busiest month of the year for new families joining Unique, many through our new online form.

##### **Providing Information and Support to Families When They Need us Most:**

Our 'Listening Ear' helpline staff answered 9,500 emails and 877 calls from families plus a further 1,600 from medical and other professionals. We also saw an increase in requests for help via social media, the increased workload presenting a challenge for staff but one that they rose to with their customary professionalism. With increasingly complex diagnoses, representing ever smaller changes in a person's genetic makeup, such requests for help demand ever greater focus, understanding and depth of input from our team. Trustees are proud of the way in which they have responded.

Through our 'Unique Information Project', we produced 11 brand new information guides to specific RCDs and novel single gene disorders, the latter only recently detectable with newly-improved technology. We also completed substantial updates to three of our existing guides, based largely on information provided by member families, a fantastic example of self help and mutual support. The needs of our diverse community are also reflected in the fact that a further 23 information guides were translated (free of charge by volunteers) for those for whom English is not their first language. We now have guides in 12 languages, including Arabic, Polish, German, Spanish and Russian and are grateful to those who have given their time to translate them. One mum wrote to us recently to say:

***“Since my son was diagnosed, we have passed out your information guide to new teachers/therapists/doctors as a basic ‘get to know me’ reference. This has been such a valuable resource. Thank you.”***

We continued to update database entries for members. Their information is used to answer queries, produce information guides, match families and support health professionals and researchers.

Our Family Support Officer also produced seven new 'practical guides', covering more general, highly relevant topics for families. We now have a library of more than 20. New guides published during the year included diverse topics such as Toilet Training, Travel Insurance and Behaviour. All are free from our website or in hard copy from staff. A specialist in Neurodevelopmental disorders said of our behaviour guide: ***“It's really great. I'll certainly be directing families to this helpful resource.”***



## **Rare Chromosome Disorder Support Group**

### **Report of the trustees**

#### **For the year ended 31 March 2018**

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##### **Bringing Families Together**

Our series of regional family days continued with events in the North West (in Warrington) and in London. The latter was a first for Unique, as despite having over 300 member families in the capital, we have never held an event there. Each was attended by over 150 family members, including children with RCDs and their siblings. Families get together with other Unique families locally to get to know them, swap tips and resources and form lasting support networks. In Warrington we were delighted to be joined by geneticists from North West Regional Genetics Service/Manchester Centre for Genomic Medicine and in London from the NE Thames Regional Genetics Laboratory and Great Ormond Street Hospital, all giving up their Sundays to be with us. They gave hands-on demonstrations explaining genetic testing and test results and spent lots of time talking with families to answer their many questions.

Through our family matching service, we linked hundreds of member families whose children (and adult family members) have similar RCDs and/or symptoms, for mutual support, to swap tips and resources, chat and meet up if they wish. In addition, our Facebook 'Cafe', a secret, post-moderated group provided a safe, supportive network for families to chat and 'meet virtually', and now has over 5,000 members. This continues to relieve some of the pressure from our frontline services.

##### **Raising Awareness of Rare Chromosome and Gene Disorders**

The fourth global Rare Chromosome Disorder Awareness Week in June 2017 was the most successful yet. Celebrities 'Honey G' and Josh Gad promoted our work to their many thousands of social media followers, we received coverage in the media and on growing blog sites such as 'Selfish Mother' and our Facebook photo frame was used over 4,800 times. Other activities included presentations to diverse audiences, including our CEO Dr. Searle giving a presentation to staff at the Royal College of Nursing, a well-attended open garden weekend held by one of our trustees, lots of people holding bake sales using our Big Blue Bake Kit and a successful online Q & A session with our frontline staff.

In addition to over 24,000 Facebook followers, we now have over 5,500 Twitter followers and almost 1,000 Instagram followers. These are cost effective ways to raise awareness, promote the charity, raise funds and crucially, to reach more families and professionals to ensure those affected receive the support they desperately need.

Through the year, staff gave presentations and took part in events to raise Unique's profile and raise awareness about RCDs. These included presentations to healthcare students taking the MSc Genomic Medicine course at Imperial College, London and at the University of Southampton and to clinicians on a rare disease study day at The Sheffield Institute for Translational Neuroscience. We secured a free slot at the Festival of Genomics after requesting that patient support groups be included. Our staff chaired and participated in a Panel Discussion "For Patients, With Patients; Learning from Patient Experiences to Maximise the Benefits of Clinical Genomics".

Our CEO Dr. Searle participated in an invitation-only expert discussion at the Royal College of Anaesthetists to help develop new guidance. The Joint Committee on Genomics in Medicine in collaboration with the British Society for Genetic Medicine and NHS England is revising and updating professional guidelines on consent and confidentiality in genetic and genomic medicine.

## Rare Chromosome Disorder Support Group

### Report of the trustees

#### For the year ended 31 March 2018

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Dr. Searle participated as a patient representative at the launch of ERN-Ithaca, the new European Reference Network for rare congenital malformations and rare intellectual disability, which includes RCDs. This network will seek to enhance the lives of patients by ensuring equity of access to patients throughout the EU, disseminating good practice to optimise patient care, upskill the workforce in less well-developed centres and facilitating research and future clinical treatment trials.

#### Infrastructure

Trustees and staff continued to strengthen Unique's infrastructure during the year, reviewing our practices for data processing and storage. One Trustee was dedicated to working with senior staff to ensure the charity is ready for the changes in data protection legislation, in effect from May, 2018. Sensitive medical information is held securely and only accessed by staff on a hierarchical basis. It is treated in strict confidence in accordance with the General Data Protection Regulation (GDPR).

#### Volunteers

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

- More than 200 people continuing to volunteer as Unique local contacts. Many are or have been parents of children with RCDs and they are on hand to offer support to member families in their area, signposting them to local groups and 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 giving up their time to translate our information guides into a variety of different languages to help those for whom English is not their first language;
- A number of others assisting in areas such as marketing and promotional activities; and
- Hundreds of our members and supporters undertaking voluntary fundraising.

#### Financial Review 2017-18

##### Income

Our total income for the year is £288,592, an 11% decrease on the previous year. Our unrestricted income from donations and fundraising from members and supporters, corporate, trusts and foundations totalled £251,355. Being relatively high as a proportion of our overall income affords some welcome flexibility to Trustees to apportion funds where they are most needed. This also reduces our reliance on 3rd party organisations for funding, much of which can be for a fixed-term and tightly restricted. From charitable trusts and foundations we received unrestricted funding of £19,000 and restricted income of £35,179. 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 £315,855, down 11.5% on the previous year as Trustees acted to protect the charity in the face of falling income. 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 £12,921 as we continued to benefit from a Google Grant covering search engine advertising costs, for which we are grateful.

## **Rare Chromosome Disorder Support Group**

### **Report of the trustees**

#### **For the year ended 31 March 2018**

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##### **Level of Reserves**

The Trustees have decided to adopt a policy, reviewed annually, of holding a minimum reserve equivalent to four months' average operating costs for the previous year (not including the value of donations in kind). The Trustees have budgeted for reserves for 2018-19 of not less than £120,000.

In another challenging year for the wider charity sector, Trustees ensured expenditure remained tightly under control. Reserves at the end of the year are at £279,580, with unrestricted reserves standing at £273,150. Unrestricted reserves protect our current and future beneficiaries, safeguarding key services to ensure the charity's future sustainability. Trustees have once again decided to designate £40,000 to protect the Listening Ear Telephone and Email helpline service.

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

Our strategic plan, covering the period 2017-22 underpins our activities. Our brand new, fully mobile-responsive website (described above) is a key part of our digital upgrade, one of the strands of our strategy for expanding our reach. As described above, we made good progress with other strategic aims, including expanding our information resources, building on the success of our awareness week to reach a wider audience and holding more of our regional family days.

In a challenging climate, particularly for small charities, we will continue our diverse fundraising efforts to avoid over-reliance on one particular income strand. Staff and Trustees remain fully aware of the charity's statutory responsibilities in the area of fundraising. By minimising risk Trustees seek to ensure Unique's long-term sustainability to protect beneficiaries.

##### **Structure, Governance and Management**

The Trustees delegate day-to-day management of the charity's activities to Dr. Beverly Searle, Chief Executive Officer (CEO). Unique currently employs nine staff, 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**

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

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

##### **Management of Risk**

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

##### **Compliance and Training**

Given the importance to our work of personal and sensitive medical data, staff and trustees are aware of the requirements of data protection law and have received training in this area. Our COO 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. It is our policy that all staff and trustees who come into contact with children as part of their roles undergo a DBS check as necessary.

## **Rare Chromosome Disorder Support Group**

### **Report of the trustees**

#### **For the year ended 31 March 2018**

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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 nine Trustees with diverse backgrounds including law, business, marketing, finance, accounting, IT, the charity sector and education. Trustees are recruited by advertising as widely as possible, through our own networks and more widely. 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 2017 and are kept informed by the Company Secretary.

#### **Statement of Responsibilities of the Trustees**

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

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

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

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

## **Rare Chromosome Disorder Support Group**

### **Report of the trustees**

#### **For the year ended 31 March 2018**

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In so far as the trustees are aware:

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

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

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

#### **Auditors**

Godfrey Wilson Limited were 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 23 November 2018 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**

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#### **Opinion**

We have audited the financial statements of Rare Chromosome Disorder Support Group (the 'charity') for the year ended 31 March 2018 which comprise the statement of financial activities, balance sheet and the related notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102: The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 March 2018 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

#### **Basis for opinion**

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

#### **Conclusions relating to going concern**

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

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

#### **Other information**

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

## **Independent auditors' report**

### **To the members of**

#### **Rare Chromosome Disorder Support Group**

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

We have nothing to report in this regard.

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

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

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

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

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

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

#### **Responsibilities of the trustees**

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

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

## **Independent auditors' report**

**To the members of**

### **Rare Chromosome Disorder Support Group**

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

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

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

#### **Use of our report**

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

Date:

**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 2018

	Note	Restricted £	Unrestricted £	2018 Total £	2017 Total £
<b>Income from:</b>					
Donations and legacies	3	2,058	243,962	<b>246,020</b>	301,186
Charitable activities:					
<i>Family support services</i>	4	20,329	-	<b>20,329</b>	9,202
<i>Information and awareness</i>	5	14,850	5,652	<b>20,502</b>	12,174
Investments		-	1,741	<b>1,741</b>	2,556
<b>Total income</b>		<u>37,237</u>	<u>251,355</u>	<u><b>288,592</b></u>	<u>325,118</u>
<b>Expenditure on:</b>					
Raising funds		-	55,683	<b>55,683</b>	61,214
Charitable activities:					
<i>Family support services</i>		25,861	110,508	<b>136,369</b>	167,292
<i>Information and awareness</i>		15,971	107,832	<b>123,803</b>	128,368
<b>Total expenditure</b>	6	<u>41,832</u>	<u>274,023</u>	<u><b>315,855</b></u>	<u>356,874</u>
<b>Net expenditure and net movement in funds</b>	8	(4,595)	(22,668)	<b>(27,263)</b>	(31,756)
<b>Reconciliation of funds</b>					
Total funds brought forward		<u>11,025</u>	<u>295,818</u>	<u><b>306,843</b></u>	<u>338,599</u>
<b>Total funds carried forward</b>		<u>6,430</u>	<u>273,150</u>	<u><b>279,580</b></u>	<u>306,843</u>

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

## Rare Chromosome Disorder Support Group

### Balance sheet

As at 31 March 2018

	Note	£	2018 £	2017 £
<b>Fixed assets</b>				
Tangible fixed assets	11		<b>3,541</b>	6,679
Investments	12		<b>700</b>	700
			<b>4,241</b>	7,379
<b>Current assets</b>				
Stock	13	<b>1,567</b>		1,711
Debtors	14	<b>12,957</b>		7,938
Cash at bank and in hand		<b>272,703</b>		305,863
		<b>287,227</b>		315,512
<b>Creditors: amounts due within 1 year</b>	15	<b>11,888</b>		16,048
<b>Net current assets</b>			<b>275,339</b>	299,464
<b>Net assets</b>	16		<b>279,580</b>	306,843
<b>Funds</b>	17			
Restricted income funds			<b>6,430</b>	11,025
Unrestricted funds:				
Designated funds			<b>40,000</b>	40,000
General funds			<b>233,150</b>	255,818
<b>Total charity funds</b>			<b>279,580</b>	306,843

Approved by the trustees on 23 November 2018 and signed on their behalf by

Edna Knight - Trustee (Life President)

Helen Campbell - Trustee (Chair)

## Rare Chromosome Disorder Support Group

### Notes to the financial statements

For the year ended 31 March 2018

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#### 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 executor(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 probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material.

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

## Rare Chromosome Disorder Support Group

### Notes to the financial statements

#### For the year ended 31 March 2018

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##### **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	14.0%
Family support services	30.5%
Information and awareness	55.5%

##### **i) Tangible fixed assets**

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

Computer equipment	4 years straight line
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Items of equipment are capitalised where the purchase price exceeds £500.

## Rare Chromosome Disorder Support Group

### Notes to the financial statements

#### For the year ended 31 March 2018

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**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) Cash at bank and in hand**

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

**n) Creditors**

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

**o) Financial instruments**

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

**p) Foreign currency**

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

**q) Pension costs**

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

**r) Operating leases**

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2018

2. Prior period comparatives

	Restricted £	Unrestricted £	2017 Total £
<b>Income from:</b>			
Donations and legacies	900	300,286	<b>301,186</b>
Charitable activities			
<i>Family support services</i>	9,202	-	<b>9,202</b>
<i>Information and awareness</i>	5,771	6,403	<b>12,174</b>
Investments	-	2,556	<b>2,556</b>
<b>Total income</b>	<b>15,873</b>	<b>309,245</b>	<b>325,118</b>
<b>Expenditure on:</b>			
Raising funds	95	61,119	<b>61,214</b>
Charitable activities			
<i>Family support services</i>	20,247	147,045	<b>167,292</b>
<i>Information and awareness</i>	4,973	123,395	<b>128,368</b>
<b>Total expenditure</b>	<b>25,315</b>	<b>331,559</b>	<b>356,874</b>
<b>Net movement in funds</b>	<b>(9,442)</b>	<b>(22,314)</b>	<b>(31,756)</b>

3. Donations and legacies

	Restricted £	Unrestricted £	2018 Total £	2017 Total £
Grants > £5,000:				
D & J Hunter Charitable Trust	-	15,000	<b>15,000</b>	10,000
Grants < £5,000	-	4,000	<b>4,000</b>	3,050
Donated goods / services *	-	12,921	<b>12,921</b>	26,640
General donations	562	42,590	<b>43,152</b>	53,223
Corporate donations	-	18,999	<b>18,999</b>	25,234
Overseas donations	-	11,084	<b>11,084</b>	7,169
Gift aid	-	19,539	<b>19,539</b>	25,565
Give As You Earn (GAYE)	-	1,254	<b>1,254</b>	1,315
Pyramids	-	431	<b>431</b>	473
Legacy	-	4,230	<b>4,230</b>	3,053
Donations from fundraising activities	1,496	113,914	<b>115,410</b>	145,464
<b>Total donations and legacies</b>	<b>2,058</b>	<b>243,962</b>	<b>246,020</b>	<b>301,186</b>

\* Donated services consist of the following:

	2018 £	2017 £
Google AdWords (free web advertising)	<b>12,921</b>	<b>26,640</b>

## Rare Chromosome Disorder Support Group

### Notes to the financial statements

For the year ended 31 March 2018

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#### 4. Charitable activities: family support services

	Restricted £	Unrestricted £	2018 Total £	2017 Total £
Grants > £5,000:				
DM Thomas Foundation for Young People	9,229	-	<b>9,229</b>	-
Grants < £5,000	<u>11,100</u>	<u>-</u>	<u><b>11,100</b></u>	<u>9,202</u>
<b>Total family support services</b>	<u><u>20,329</u></u>	<u><u>-</u></u>	<u><u><b>20,329</b></u></u>	<u><u>9,202</u></u>

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

	Restricted £	Unrestricted £	2018 Total £	2017 Total £
Grants < £5,000	14,850	-	<b>14,850</b>	5,771
Christmas card and merchandise sales	<u>-</u>	<u>5,652</u>	<u><b>5,652</b></u>	<u>6,403</u>
<b>Total information and awareness</b>	<u><u>14,850</u></u>	<u><u>5,652</u></u>	<u><u><b>20,502</b></u></u>	<u><u>12,174</u></u>

## The Rare Chromosome Disorder Support Group

### Notes to the financial statements

For the year ended 31 March 2018

#### 6. Total expenditure

	Raising funds £	Family support £	Information and awareness £	2018 Total £	2017 Total £
Staff costs (note 9)	32,745	91,890	73,212	<b>197,847</b>	207,386
Training and other staff costs	11	426	3,139	<b>3,576</b>	569
Postage and distribution	654	12,302	2,584	<b>15,540</b>	27,390
Printing and design	-	7,099	2,947	<b>10,046</b>	13,777
Stationery	266	886	1,157	<b>2,309</b>	1,904
Subscriptions, licences and charges	11,085	178	3,214	<b>14,477</b>	15,767
Travel and subsistence	70	790	413	<b>1,273</b>	4,240
Room hire and event costs	45	6,763	55	<b>6,863</b>	16,268
Computer expenses	4,851	1,282	2,341	<b>8,474</b>	10,229
Office costs	448	2,208	2,154	<b>4,810</b>	6,135
Office rent	2,504	5,751	10,295	<b>18,550</b>	17,030
Website and database development	-	216	10,080	<b>10,296</b>	193
Advertising **	1,809	3,941	7,399	<b>13,149</b>	26,640
Insurance	284	618	1,125	<b>2,027</b>	2,366
Audit and accountancy	487	1,062	1,931	<b>3,480</b>	3,336
Depreciation	424	957	1,757	<b>3,138</b>	3,487
Loss on disposal of fixed asset	-	-	-	-	157
<b>Total expenditure</b>	<b>55,683</b>	<b>136,369</b>	<b>123,803</b>	<b>315,855</b>	<b>356,874</b>

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



## The Rare Chromosome Disorder Support Group

### Notes to the financial statements

#### For the year ended 31 March 2018

#### 7. Support and governance costs

Support and governance costs are allocated to activities as follows:

	Raising funds	Family support	Information and awareness	2018 Total	2017 Total
	£	£	£	£	£
Staff costs	2,696	5,873	10,687	<b>19,256</b>	24,043
Training and other staff costs	3	6	11	<b>20</b>	387
Postage and distribution	6	13	24	<b>43</b>	3,816
Stationery	2	4	7	<b>13</b>	40
Subscriptions, licences and charges	56	123	223	<b>402</b>	425
Travel and subsistence	14	31	57	<b>102</b>	102
Room hire and event costs	-	-	-	-	38
Computer expenses	-	-	-	-	700
Office costs	37	79	144	<b>260</b>	904
Office rent	-	-	-	-	17,030
Advertising	1,809	3,941	7,171	<b>12,921</b>	26,640
Insurance	284	618	1,125	<b>2,027</b>	2,366
Audit and accountancy	487	1,062	1,931	<b>3,480</b>	3,336
Depreciation	-	-	-	-	3,487
Loss on disposal of fixed asset	-	-	-	-	157
	<u>5,394</u>	<u>11,750</u>	<u>21,380</u>	<u><b>38,524</b></u>	<u>83,471</u>
<b>Total support and governance costs</b>	<b>5,394</b>	<b>11,750</b>	<b>21,380</b>	<b>38,524</b>	<b>83,471</b>

## Rare Chromosome Disorder Support Group

### Notes to the financial statements

#### For the year ended 31 March 2018

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#### 8. Net movement in funds

This is stated after charging:

	<b>2018</b>	2017
	<b>£</b>	£
Depreciation	<b>3,138</b>	3,487
Trustees' remuneration	<b>Nil</b>	Nil
Trustees' reimbursed expenses	<b>Nil</b>	Nil
Auditors' remuneration:		
▪ Statutory audit (including VAT)	<b>3,480</b>	3,336
	<b><u>3,480</u></b>	<b><u>3,336</u></b>

#### 9. Staff costs and numbers

Staff costs were as follows:

	<b>2018</b>	2017
	<b>£</b>	£
Salaries and wages	<b>178,312</b>	188,840
Social security costs	<b>12,720</b>	13,096
Pension contributions	<b>6,815</b>	5,450
	<b><u>197,847</u></b>	<b><u>207,386</u></b>

No employee earned more than £60,000 during the year (2017: none).

The key management personnel of the charity comprise the trustees, the Chief Executive and the Chief Operating Officer. The total employee benefits comprising gross wages, employer pension contributions and employer NI contributions received by the charity's key management personnel in the period was £90,526 (2017: £87,724).

	<b>2018</b>	2017
	<b>No.</b>	No.
Average staff head count	<b>9.00</b>	9.00
Average full time equivalent	<b>6.00</b>	6.00

#### 10. Taxation

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

## Rare Chromosome Disorder Support Group

### Notes to the financial statements

For the year ended 31 March 2018

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#### 11. Tangible fixed assets

	Computer Equipment £
<b>Cost</b>	
At 1 April 2017	23,919
Additions in year	-
Disposals	<u>(1,691)</u>
At 31 March 2018	<u>22,228</u>
<b>Depreciation</b>	
At 1 April 2017	17,240
Charge for the year	3,138
On disposal	<u>(1,691)</u>
At 31 March 2018	<u>18,687</u>
<b>Net book value At 31 March 2018</b>	<u><u>3,541</u></u>
At 31 March 2017	<u><u>6,679</u></u>

#### 12. Investments

	Artwork £
<b>At 31 March 2018</b>	<u><u>700</u></u>
At 31 March 2017	<u><u>700</u></u>

A Tracey Emin print was donated in 2005. The trustees have no immediate plans to sell the print consequently it has been reported as a fixed asset investment in the accounts. It is valued at the average of two professional valuations which were provided in May 2012. No revaluations were carried out in the year. The trustees are satisfied that the print is carried at an appropriate value at 31 March 2018.

#### 13. Stock

	2018 £	2017 £
Merchandise	<u><u>1,567</u></u>	<u><u>1,711</u></u>

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2018

14. Debtors

	2018 £	2017 £
Trade debtors	128	265
Prepayments	7,782	7,673
Accrued income	5,047	-
	<u>12,957</u>	<u>7,938</u>

15. Creditors : amounts due within 1 year

	2018 £	2017 £
Trade creditors	-	129
Credit card	-	194
Accruals	7,459	11,511
Other taxation and social security	3,770	4,214
Pension creditor	659	-
	<u>11,888</u>	<u>16,048</u>

16. Analysis of net assets between funds

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

Analysis of net assets between funds - prior period comparative

	Restricted funds £	Designated funds	Unrestricted funds £	Total funds £
Tangible fixed assets	-	-	6,679	6,679
Investments	-	-	700	700
Net current assets	11,025	40,000	248,439	299,464
<b>Net assets at 31 March 2017</b>	<u>11,025</u>	<u>40,000</u>	<u>255,818</u>	<u>306,843</u>

## Rare Chromosome Disorder Support Group

### Notes to the financial statements

For the year ended 31 March 2018

#### 17. Movements in funds

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

#### Purposes of restricted funds

##### **Family support services**

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

##### **Information and awareness**

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

#### Purposes of designated funds

##### **Listening Ear Fund**

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

## Rare Chromosome Disorder Support Group

### Notes to the financial statements

For the year ended 31 March 2018

#### Prior period comparative

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

#### 18. Operating leases

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

	2018 £	2017 £
Amount falling due:		
Within 1 year	<b>18,600</b>	18,600
Within 2 - 5 years	<u><b>7,750</b></u>	<u>26,350</u>

#### 19. Related party transactions

There were no related party transactions during the financial year ended 31 March 2018, or the prior year. The charity received donations from trustees and key management personnel during the year of £1,437 (2017: £1,445).