Company no. 05460413
Charity no. 1110661

The Rare Chromosome Disorder Support Group

Report and Audited Financial Statements

31 March 2014

The Rare Chromosome Disorder Support Group

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For the year ended 31 March 2013

The Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2014

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
Sally Cohen	Vice Chairman, Trustee
Edna Knight, MBE	Founder, Life President, Trustee
Gillian Manvell	Trustee
Isobel Hindle (appointed 16 July 2013)	Trustee
Fiona de Zoete (appointed 1 May 2013)	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 TSB PO Box 545 Faryners House 25 Monument Street London EC3R 8BQ
Auditors	Godfrey Wilson Ltd Chartered accountants and statutory auditors Unit 5.11 Paintworks Bath Road Bristol BS4 3EH

The Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2014

For Unique 2013 has been another year of continued record increase in membership - 1,265 new members coming to us for specialist information and support after their child or their own diagnosis of a rare chromosome disorder.

This reflects the technical advances in genetic testing that have lead to a massive increase in the rate of diagnosis of rare chromosome disorders over the last four years. We expect this trend to continue as more and more families affected by microdeletions, microduplications and increasingly small genomic rearrangements come to Unique for help - in addition to those affected by larger chromosome disorders who we have been seeing over the 30 years since Unique was founded.

Many families come to us distressed, struggling to come to terms with their child's diagnosis, often feeling isolated and confused. We are there to help and guide them to understand the diagnosis and face the future. Despite the rapid increase in demand, all receive the same excellent service that has become Unique's hallmark whether it is information on and explanations of their diagnosis; putting them in touch with families affected by similar disorders; helping them to build support networks with other families locally and worldwide.

The range of issues faced by our families has never been wider, ranging from learning difficulties, behavioural problems and autism, to complex medical conditions from epilepsy, heart defects and to physical disabilities. Many of our newer families face the challenge of having children with no obvious physical symptoms but complex learning needs and behaviours and who may therefore find it more difficult to obtain appropriate support for their children.

As well as supporting families directly we continue to develop relationships with the medical professionals who look after our families: providing them with anonymised data on chromosome disorders to support their patients, sharing data on particular chromosome disorders through our chromosome-specific information guides and participating in many advisory boards and professional committees such as that which developed the first UK rare disease strategy launched in November 2013.

2013 saw the launch of our new website – a fantastic resource for families and professionals alike with information on the rare chromosome disorders which we cover, the 150 guides we have published to specific disorders and much more.

Following the successful pilot event we held in East Anglia, we held two further family social events during the year in the West Midlands and the North East. Each was well attended and very successful, bringing together families from across each region to meet others living with similar challenges to establish ongoing mutual support networks.

Of course none of this would be possible without the hard work and dedication of our wonderful team of staff and volunteers, the support of trusts and foundations like Rank Foundation and Awards for All and the amazing efforts of a great many members, their friends and families, who go out of their way to fundraise for Unique, running marathons, holding cake sales and coffee mornings, completing obstacle courses and even shaving off their hair. Thank you.

Sophie Sainty, Chair of Trustees June 2014

The Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2014

Aims and objectives

Each year many hundreds of babies are born with Rare Chromosome Disorders (RCDs). These lifelong conditions, often causing severe physical and learning disabilities, involve parts of one or more of their chromosomes being missing, added on or rearranged. Many of those affected will be totally reliant on their parents and carers throughout their lives and though individual disorders are rare, some quite literally 'unique', added together they affect at least 1 in 200 live-born babies. Despite this, they remain poorly understood by many doctors and other health professionals. This can leave parents, already struggling to come to terms with their child's diagnosis, with lots of unanswered questions and feeling distressed and confused.

Through the provision of specialist information and support, Unique aims to beat the often desperate isolation of all those affected. By giving parents and carers answers to many of their questions, we can help them face the future with renewed hope. We also work to raise awareness of the disorders among medical and other professionals and the wider public to develop a better understanding of the demands they place on those affected and their families.

Our aims and objectives can be summarised as:

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

How *Unique* helps: key services

Support for families:

- ***Unique's*** **Listening Ear telephone and email helpline** is staffed by our experienced team, on hand to explain complex terminology and help families understand their child's diagnosis. Often the first point of contact for distressed parents of a newly-diagnosed child as well as professionals needing information to help them counsel and plan patient care.
- **Our family matching service** links those living with similar conditions to share their experiences, offering invaluable mutual support.
- **Events for families to meet** such as one-day social events, study days and family conferences, bring together families and professionals to further our knowledge of specific RCDs and develop the means to offer improved support.

Provision of specialist information:

- **The *Unique* information project** has produced over 150 guides to specific RCDs, using evidence provided by our member families and data from published medical literature. The guides are written in family-friendly language, are independently medically-verified and available free of charge from our website or from Unique staff. We have also produced a number guides to more general topics requested by families.

- **Our specialist database/patient registry** comprehensively documents the in-depth natural histories of those living with RCDs. As well as medical data, it contains behavioural, social, educational and developmental information provided by Unique member families and is used daily by researchers, geneticists and other professionals to assist in their work. Sensitive medical information is treated in the utmost confidence and is held securely.
- **Our website** contains a wealth of information and sources of help and attracts around 10,000 visitors per week.
- **The Unique magazine** is published three times per year, packed with information, updates from families, resources and fundraising ideas.
- **Our network of over 200 local volunteer contacts** support families in their area, signposting them to local services and much-needed resources.

The charity's strategic direction

During the year, trustees and key staff reviewed and updated our operating plan for 2012-2015. Our focus remains on developing frontline services (specialist information and family support) to meet rapidly increasing demand from families desperate for our help. Priorities include:

- further development of our specialist database;
- increasing capacity of our information and family support; and
- further strengthening our fundraising efforts to support our objectives.

Vision, mission, 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. The next 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 2013-14

For the fourth year in a row, record numbers of families approached us for help in 2013-14. Over 1,260 new members joined us, a 9.5% increase on the previous year, taking our total membership to over 11,000 member families, i.e. over 14,000 individuals affected by a RCD. This ongoing, huge increase in demand is due to ever more sophisticated diagnostic technology and professionals increasingly referring families to us, reflecting their strong belief in the value and quality of our work.

The Rare Chromosome Disorder Support Group

Report of the trustees

For the year ended 31 March 2014

Information project

- We produced 17 new information guides to specific rare chromosome disorders, reaching the significant milestone of our 150th Information Guide.
- 11 of our existing information guides were substantially updated, drawing on new information gathered from our member families about their children (and increasingly adults).
- Volunteers translated a further 19 guides into a variety of languages for those for whom English is not their mother tongue. We now have information guides in 11 languages, including Arabic, Polish, French and Spanish and this year produced our first guide in Portuguese!
- We continued to supplement our information team with Dr Catherine Whitlock, a freelance Science writer, assisting the team with researching and writing our information guides.
- Our staff continued the production of more-generic guides, covering topics including genetic testing procedures such as Whole Genome and Exome DNA Sequencing, sleep and communication issues.

To illustrate how families use our guides, one parent wrote to thank us recently, saying:

"Since my son was diagnosed, we have printed and passed out this guide to new teachers/therapists/doctors as a basic "get to know me" reference. Now when I tell them that this information is about my son, I will mean that literally!"

With technology used for diagnosing chromosome disorders becoming ever more sophisticated, many more children are receiving a diagnosis and demand for our services is rocketing. Families often require carefully tailored responses about very rare and newly-emerging disorders for which there is little or no publicly available information. Our staff have met this increased demand with the same excellent levels of service to families, testament to their professionalism and sheer dedication, for which we are enormously grateful.

Family support services

- Our Listening Ear team answered over 15,000 telephone and email queries from families, plus a further 2,000 from medical and other professionals. All were provided with information and support that is quite simply not available elsewhere.
- We strengthened the team by recruiting a new Information Officer to support families. Cathryn Moss is a registered Genetic Counsellor who brings a skillset that will be of real benefit to new and existing Unique member families.
- We continued contacting all members to update their database entries, the bedrock of the information and support we provide to parents and carers, health professionals and researchers.
- Our Family Support Officer continued to support all new and existing members and provide details of a huge range of resources to help them care for their disabled children.
- Our post-moderated discussion groups on Facebook went from strength to strength, with our main Facebook page reaching the milestone of 10,000 'likes'. These groups continue to be a lifeline for many families who feel part of a much wider community.
- The 'Unique awareness card', carried by family carers to explain their child's condition, has now been provided to more than 300 carers. Many have contacted us to say they have been used successfully in a variety of settings, including restaurants, at theme parks and and airports.

- Our website is a comprehensive source of support to families and professionals and was completely redesigned and re-launched during the year, to very positive feedback. It contains a newly-commissioned video explaining how families are affected and how Unique has helped them.

Facilitating networks for families and professionals

- Building on our successful pilot in March 2013, we held two more family social events, combined with training for local volunteer contacts. Funded by the generous support of Awards for All, part of the Big Lottery Fund, they took place in the West Midlands in October 2013 and the North East in March 2014, bringing families together to get to know each other and form informal local support networks. The local volunteers were brought up to speed with everything Unique and helped to better understand how their efforts can best be directed. Both events were a great success, each attended by over 50 adults and 50 children and by laboratory-based geneticists (from the West Midlands and Northern Genetics services respectively) who gave demonstrations about genetic testing and were on hand to answer questions from parents. This is a model we are aiming to develop further in the future with more one-day events around the country.
- We continued to build and strengthen relationships with health and other professionals and have close links with specialists at hospitals and Regional Genetics Centres across the country.
- We have worked closely with other third sector organisations including Genetic Alliance UK, Rare Disease UK and SWAN UK. Our CEO Dr Searle sits on the SWAN UK Advisory committee.
- Our 'local-to-you' Facebook groups link members in their locality and a number of them have formed informal groups to support each other. We have a confidential Facebook 'Cafe' for people to seek informal tips and guidance which has more than 2,000 members.
- Our regular email news bulletins are a cost-effective way to reach people and go to thousands of interested parties. We also have an active Twitter feed with more than 2,300 followers.

Awareness-raising and collaboration

The rarity of individual RCDs means that our awareness raising activities, particularly among professionals, are a key objective. Highlights included:

- Participating in the EACH study (Evaluation of Array Comparative Genomic Hybridisation in prenatal diagnosis of foetal anomalies) with Newcastle University.
- Our CEO Dr. Beverly Searle being invited to speak at the Rare Disease reception in the Houses of Parliament in London, of particular importance given the launch of the UK's very first rare disease strategy this year.
- Our Information Officer, Dr. Sarah Wynn becoming one of the patient/public representatives for the Clinical Reference Group (CRG) for Genetics. The clinical reference groups are responsible for the specialised commissioning of genetics within the NHS.
- Staff sitting on professional advisory boards including the Wellcome Trust Sanger Decipher and 'Deciphering Developmental Disorders' (DDD) projects.
- Dr. Searle presenting at the induction day for the new training programme for young NHS Healthcare Science Trainees.
- Again hosting an awareness-raising stand at the British Society of Genetic Medicine conference.

- Giving further teaching sessions to medical students at University College, London.
- Working with a team from the University of Oxford on the development of materials to help families explain to their child about a sex chromosome abnormality.
- Dr. Searle giving a keynote address at the 16th meeting of the Irish Society of Human Genetics.
- Continuing to work with the University of Southampton in an advisory capacity on research studies looking at Incidental Findings in Genetic Tests and Predictive Genetic Testing of Children for Adult Onset conditions.

Challenges

With limited resources, we face the significant challenge of how best to develop the charity's capacity to meet rapidly increasing demand. To this end we continued to invest in fundraising during the year, aiming to further diversify our income to ensure we are not reliant on one particular income stream. During the year Craig Mitchell, our Chief Operating (COO) passed with merit the Institute of Fundraising's Diploma in Fundraising course and we took the decision that in 2014-15 we will employ our first part-time staff fundraiser. We have also invested in key, frontline services such as our Listening Ear and specialist database/registry. Safeguarding and building these areas is key to ensuring we can help families when they are most in need.

Volunteers

We are extremely grateful to a great many people who gave up their time to support us, including:

- 219 Unique members volunteer as local contacts, helping support members in their area, signposting them to local resources, holding social events and by just being there to listen.
- 34 geneticists, medical and other professionals checking and verifying our published information on a wide range of chromosome disorders.
- 25 volunteers involved in translating our information guides into other languages.
- A number of others who helped with our IT needs, marketing and promotional activities and despatching merchandise.

Financial review

Income

Unique's income for 2013-14 is £272,222. Of this total, our unrestricted income from trusts and foundations, donations and fundraising from members and supporters totalled £203,382. Unrestricted income is particularly welcome as it allows us to direct funds to where they are most needed and plan for the future with confidence. From charitable trusts and foundations we received unrestricted funding of £18,750 and restricted income of £68,840, covering costs associated with family support in various regions across the UK, events for families and published information guides.

Expenditure

Total expenditure for the year was £265,692 which was comfortably within budget, reflecting the sound financial management procedures we have in place.

The ascribed value of donated services for the year is £7,472. Throughout the year we continued to benefit from a Google Grant covering search engine advertising costs.

Reserves policy
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 2014-15 of not less than £86,000.

In uncertain times, we continued to budget prudently, carefully controlling our expenditure. Total funds at the end of the year are at £282,261 with unrestricted reserves standing at £270,756. This enables us to safeguard key services in the face of rising demand and helps us plan with confidence. Trustees have once again decided to designate £40,000 to protect the Listening Ear Telephone and Email helpline service. Restricted reserves of £11,505 consist predominantly of grants towards regional events, regional family support and information guides.

Plans for 2014-15
Prudent budgeting means we have sufficient resources to continue to develop our infrastructure and services that are of direct benefit our members. Plans for the year include:

- Continuing the full upgrade of our database/registry of RCDs and of our finance and fundraising systems.
- Adding further information guides to our unique library of published resources for families and professionals.
- Investing in additional staffing resources in areas such as fundraising and specialist information provision.
- Running two family conference weekends at which families can learn more about RCDs, one in the North of England (planned for Blackpool in May 2014) and one in the South (in Bristol in October 2014).
- Working with other organisations across the world to run the very first Rare Chromosome Disorder Awareness week, planned for June 2014.

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 seven, including the CEO, two of whom are full-time and five part-time. Craig Mitchell (COO), is also Company Secretary. Until December 2013 we continued to work with a self-employed fundraiser to focus on fundraising from trusts and foundations and a self-employed science writer, helping to produce our information guides.

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, 3 of our 5 part-time staff worked exclusively from home and regularly communicated via VOIP to minimise costs and our carbon footprint.

Management of risk
Our Risk Register, containing the major risks to which the charity could be exposed, as identified by trustees and senior staff, was updated during the year. This includes contingency plans as operating conditions and/or performance change. The charity's position is kept under review and discussed in detail at each meeting of the trustees 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 attended a course run by ACAS on employing staff to ensure our procedures are fit for purpose. All staff and trustees who come into contact with children as part of their roles undergo a DBS check.

Unique has an Internal Research and Ethics Committee (comprising the CEO, the Senior Information Officer, a Medical Advisor, a trustee and an adult 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 in fundraising and IT skills during the year.

Governance
Governance and management structures of the charity are kept under constant review to ensure optimal use of resources. The board meets three times per year and holds monthly Skype meetings with key staff primarily on financial performance, enabling a proactive reaction to any income changes and to define strategy. Two new trustees were recruited during the year taking the total to six trustee-directors with backgrounds in law, business, marketing, the charity sector and education. We are in the process of recruiting a new trustee with specific responsibility for financial matters.

Registered members of the company limited by guarantee and others with an interest in Unique are invited to attend the Annual General Meeting 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 charity 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;
- 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 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.

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

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

Approved by the trustees on 13 June 2014 and signed on their behalf by

Edna Knight - Trustee (Life President)

Sophie Sainty - Trustee (Chairman)

Independent auditors' report

To the members of

The Rare Chromosome Disorder Support Group

We have audited the financial statements of The Rare Chromosome Disorder Support Group for the year ended 31 March 2014 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 2014 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

The 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:

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

GODFREY WILSON LIMITED
Chartered Accountants &
Statutory Auditors
Unit 5.11 Paintworks
Bath Road
Bristol
BS4 3EH

The Rare Chromosome Disorder Support Group

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

For the year ended 31 March 2014

	Note	Restricted £	Unrestricted £	**2014 Total £**	2013 Total £
Incoming resources					
Incoming resources from generated funds:					
Voluntary income	2	-	116,533	**116,533**	141,381
Activities for generating funds	3	-	83,424	**83,424**	87,604
Investment income		-	2,500	**2,500**	1,942
Incoming resources from charitable activities:					
Family support services	4	43,140	925	**44,065**	46,560
Information services	5	25,700	-	**25,700**	31,312
Total incoming resources		68,840	203,382	**272,222**	308,799
Resources expended					
Costs of generating funds:					
Fundraising costs		-	47,742	**47,742**	47,957
Merchandise costs		-	2,595	**2,595**	1,397
Charitable activities:					
Family support services		42,747	85,675	**128,422**	133,292
Information services		29,927	38,619	**68,546**	75,919
Governance costs		-	18,387	**18,387**	16,061
Total resources expended	6	72,674	193,018	**265,692**	274,626
Net incoming / (outgoing) resources before gains & transfers		(3,834)	10,364	**6,530**	34,173
Transfers between funds		2,244	(2,244)	**-**	-
Net movement in funds	7	(1,590)	8,120	**6,530**	34,173
Reconciliation of funds					
Total funds brought forward		13,095	262,636	**275,731**	241,558
Total funds carried forward		11,505	270,756	**282,261**	275,731

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above. Movements in funds are disclosed in Note 16 to the accounts.

The Rare Chromosome Disorder Support Group

Balance sheet

As at 31 March 2014

	Note	£	2014 £	2013 £
Fixed assets				
Tangible fixed assets	10		**1,691**	2,063
Investments	11		**700**	700
			2,391	2,763
Current assets				
Stock	12	**1,323**		1,140
Debtors	13	**8,979**		7,667
Cash at bank and in hand		**303,202**		273,403
		313,504		282,210
Creditors: amounts due within 1 year	14	**33,634**		9,242
Net current assets			**279,870**	272,968
Net assets	15		**282,261**	275,731
Funds	16			
Restricted funds			**11,505**	13,095
Unrestricted funds:				
Designated funds			**40,000**	40,000
General funds			**230,756**	222,636
Total funds			**282,261**	275,731

Approved by the trustees on 13 June 2014 and signed on their behalf by

Edna Knight - Trustee (Life President) Sophie Sainty - Trustee (Chair)

The Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2014

1. Accounting policies

a) The financial statements have been prepared under the historical cost convention and in accordance with applicable accounting standards and the Companies Act 2006. They follow the recommendations in the Statement of Recommended Practice, Accounting and Reporting by Charities (issued in March 2005).

b) Voluntary income is received by way of donations and gifts and is included in full in the statement of financial activities when receivable.

c) Revenue grants are credited to the statement of financial activities when received or receivable which ever is earlier, unless they relate to a specific future period, in which case they are deferred.

d) Resources expended are recognised in the period in which they are incurred. Resources expended include attributable VAT which cannot be recovered.

e) 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.

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

g) Restricted funds are to be used for specific purposes as laid down by the donor. Expenditure which meets these criteria is charged to the fund.

h) Unrestricted funds are donations and other incoming resources received or generated for the charitable purposes.

i) 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.

j) Stock is stated at the lower of cost and net realisable value.

2. Voluntary income

	Restricted £	Unrestricted £	**2014 Total £**	2013 Total £
Grants > £5,000:				
Smith and Williamson	-	10,000	**10,000**	-
The John Ellerman Foundation	-	-	**-**	25,000
Sylvia Adams Charitable Trust	-	-	**-**	10,000
Ernest Kleinwort Charitable Trust	-	-	**-**	5,000
Grants < £5,000	-	8,750	**8,750**	18,650
Donated goods / services *	-	7,472	**7,472**	12,442
General donations	-	43,482	**43,482**	36,846
Corporate donations	-	13,518	**13,518**	4,131
Gift aid	-	22,128	**22,128**	18,103
Give As You Earn (GAYE)	-	2,208	**2,208**	2,025
Overseas donations	-	8,037	**8,037**	8,468
Pyramids	-	938	**938**	716
Total voluntary income	-	116,533	**116,533**	141,381

* Donated services consist of the following:

	2014 £	2013 £
Google AdWords (free web advertising)	**7,472**	10,994
Storage facilities	**-**	1,448
Total donated services	**7,472**	12,442

3. Activities for generating funds

	Restricted £	Unrestricted £	**2014 Total £**	2013 Total £
Fundraising activities	-	76,452	**76,452**	81,297
Christmas card and merchandise sales	-	6,972	**6,972**	6,307
Total activities for generating funds	-	83,424	**83,424**	87,604

4. Family support services

	Restricted £	Unrestricted £	**2014 Total £**	2013 Total £
Grants > £5,000:				
Rank Foundation	12,500	-	**12,500**	12,500
Awards for All - regional events	9,690	-	**9,690**	-
Liz and Terry Bramall Foundation	5,000	-	**5,000**	-
Jeans for Genes	-	-	**-**	23,500
Grants < £5,000	15,950		**15,950**	7,000
Conference income	-	925	**925**	2,810
Magazine revenues	-	-	**-**	750
Total family support services	43,140	925	**44,065**	46,560

5. Information services

	Restricted £	Unrestricted £	**2014 Total £**	2013 Total £
Grants > £5,000:				
Rank Foundation	12,500	-	**12,500**	12,500
The President's Club	5,000	-	**5,000**	-
Grants < £5,000	8,200	-	**8,200**	9,800
Study days and support	-	-	**-**	8,744
Donations	-	-	**-**	268
Total information services	25,700	-	**25,700**	31,312

6. Total resources expended

		Fundraising costs £	Merchandise costs £	Family support services £	Information services £	Governance costs £	Support costs £	**2014 Total £**	2013 Total £
Staff costs (note 8)		30,850	-	77,992	48,968	10,562	275	**168,647**	155,708
Recruitment		-	-	-	-	-	-	**-**	119
Training		195	-	125	-	114	-	**434**	2,110
Volunteer services		-	-	-	-	-	-	**-**	144
Postage and distribution		406	21	15,686	1,169	110	114	**17,506**	17,086
Printing and design		1,047	2,574	11,242	2,412	-	199	**17,474**	19,790
Stationery		212	-	1,089	1,053	-	157	**2,511**	3,886
Subscriptions, licences and charges		9,312	-	42	3,572	599	30	**13,555**	10,257
Travel and subsistence		94	-	1,821	2,527	306	-	**4,748**	4,047
Room hire and event costs		27	-	4,790	32	124	-	**4,973**	24,496
Equipment and software		476	-	977	56	-	80	**1,589**	1,050
Books and publications		-	-	-	56	-	-	**56**	73
Office costs		167	-	2,991	952	470	935	**5,515**	5,375
Office rent		2,723	-	6,809	3,404	681	-	**13,617**	11,000
Website and database development		-	-	280	-	-	-	**280**	79
Advertising	*	-	-	-	-	-	7,472	**7,472**	10,994
Insurance		-	-	-	-	2,222	132	**2,354**	2,421
Audit and accountancy		-	-	-	-	3,000	-	**3,000**	3,000
Depreciation		-	-	-	-	-	1,458	**1,458**	1,480
Storage expenses		25	-	50	50	-	378	**503**	1,511
Sub-total		45,534	2,595	123,894	64,251	18,188	11,230	**265,692**	274,626
Allocation of support costs		2,208	-	4,528	4,295	199	(11,230)	-	-
Total resources expended		**47,742**	**2,595**	**128,422**	**68,546**	**18,387**	**-**	**265,692**	274,626

* Advertising represents entirely donated services with no cost to Unique (see note 2).

7. Net movement in funds

This is stated after charging:

	2014	2013
	£	£
Depreciation	**1,458**	1,480
Trustees' indemnity insurance	**2,222**	1,361
Trustees' reimbursed expenses	**Nil**	Nil
Auditors' remuneration:		
▪ Statutory audit (including VAT)	**3,000**	3,000

8. Staff costs and numbers

Staff costs were as follows:

	2014	2013
	£	£
Salaries and wages	**143,686**	131,958
Social security costs	**12,555**	11,450
Freelance staff	**12,406**	12,300
	168,647	155,708

No employee earned more than £60,000 during the year.

	2014	2013
	No.	No.
Average number of employees (full-time equivalent)	**5.30**	4.60

9. Taxation

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

10. Tangible fixed assets

	Total £
Cost	
At 1 April 2013	**10,283**
Additions in year	**1,086**
At 31 March 2014	**11,369**
Depreciation	
At 1 April 2013	**8,220**
Charge for the year	**1,458**
At 31 March 2014	**9,678**
Net book value	
At 31 March 2014	**1,691**
At 31 March 2013	2,063

11. Investments

	2014 **£**	2013 £
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. The trustees are satisifed that the print is carried at an appropriate value at 31 March 2014.

12. Stock

	2014 **£**	2013 £
Merchandise	**1,323**	1,140

13. Debtors

	2014	2013
	£	£
Trade debtors	**1,100**	268
Prepayments	**7,879**	7,399
	8,979	7,667

14. Creditors : amounts due within 1 year

	2014	2013
	£	£
Trade creditors	**904**	2,795
Credit card	**535**	-
Accruals	**3,400**	3,000
Other taxation and social security	**3,795**	3,447
Deferred income	**25,000**	-
	33,634	9,242

15. Analysis of net assets between funds

	Restricted funds	Unrestricted funds	**Total funds**
	£	£	**£**
Tangible fixed assets	-	1,691	**1,691**
Investments	-	700	**700**
Current assets	11,505	301,999	**313,504**
Current liabilities	-	(33,634)	**(33,634)**
Net assets at 31 March 2014	**11,505**	**270,756**	**282,261**

16. Movements in funds

	At 1 April 2013 £	Incoming resources £	Outgoing resources £	Transfers between funds £	**At 31 March 2014 £**
Restricted funds					
Conference	-	500	(500)	-	**-**
Listening Ear	4,370	12,500	(19,114)	2,244	**-**
Information Guides	5,921	25,700	(29,927)	-	**1,694**
Regional Family Funding	2,804	20,450	(16,111)		**7,143**
Regional Events	-	9,690	(7,022)	-	**2,668**
Total restricted funds	13,095	68,840	(72,674)	2,244	**11,505**
Unrestricted funds					
Designated funds:					
Listening Ear Fund	40,000	-	-	-	**40,000**
Total designated funds	40,000	-	-	-	**40,000**
General funds	222,636	203,382	(193,018)	(2,244)	**230,756**
Total unrestricted funds	262,636	203,382	(193,018)	(2,244)	**270,756**
Total funds	275,731	272,222	(265,692)	-	**282,261**

Purposes of restricted funds

Conference	This is funding from the Dame Violet Wills Will Trust for a conference in Bristol.
Listening Ear	This is funding from the Rank Foundation for the Listening Ear helpline service.
Information Guides	This is funding from various trusts and foundations (as set out in note 5) to be used for producing information guides.
Regional Family Funding	This is funding from various trusts and foundations to support families in specific regions in the UK.
Regional Events	This is funding from Awards For All for regional events.

16. Movements in funds (continued)

Purpose of designated fund

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.

Transfers between funds

Where restricted funds are overspent at the year end, a transfer is made from general funds to bring the restricted fund balance back to zero.