Company no. 05460413
Charity no. 1110661

Rare Chromosome Disorder Support Group

Report and Audited Financial Statements

31 March 2013

Rare Chromosome Disorder Support Group

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For the year ended 31 March 2013

Rare Chromosome Disorder Support Group

Reference and administrative details

For the year ended 31 March 2013

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
Gillian Manvell	Trustee
Edna Knight, MBE	Founder, Life President, Trustee
Sally Cohen	Trustee

Chief executive officer	Beverly Searle, PhD
Company secretary	Craig Mitchell
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	Bank of Ireland
Kings Hill	PO Box 27
West Malling	One Temple Quay
Kent	Bristol
ME19 4TA	BS99 7AX

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

Auditors	Godfrey Wilson Ltd Chartered accountants & statutory auditors Unit 5.11 Paintworks Bath Road Bristol BS4 3EH

Rare Chromosome Disorder Support Group

Report of the Trustees

For the year ended 31 March 2013

2012-13 was once again a record year for Unique, with more people than ever approaching us for help and information about rare chromosome disorders. For the first time, over 1,000 new members joined us (1,152 in total), an increase of more than 20% on the previous year. This on-going, rapidly-increasing demand is due to the continued roll-out of new technology used to diagnose chromosome disorders, coupled with our own awareness-raising activities. The number being diagnosed with lifelong and in many cases life-limiting rare chromosome disorders is increasing exponentially (including babies, young children and even some people being diagnosed well into adulthood), placing pressure on our frontline services.

In response, this year our focus has been on further developing our infrastructure to ensure that families faced with an often bleak diagnosis get the help and support they need. We established Unique's very first office base in May 2012, a real milestone for the charity giving our day-to-day operations a focal point and providing a space for staff and Trustees to meet. It also gives us the opportunity to make more use of volunteers to augment staff resources.

In addition, we have further developed our finance and fundraising systems – for example improving the ways we collect Gift Aid and stewardship of donors. We have succeeded in growing the charity's income (albeit by a relatively small amount) for the second consecutive year, which is encouraging given the current fundraising climate. We are extremely grateful for the multi-year grants from the John Ellerman Foundation, Rank Foundation, Garfield Weston Foundation and Sylvia Adams Charitable Trust which have enabled us to safeguard key frontline services and develop a more sustainable infrastructure. However, the increase in membership (last year's total was 60% up on the average for the previous 5 years) and resultant pressure on core services means we will need to redouble our fundraising efforts to support all those who need us.

We continue to be astonished by the lengths to which our member families (many of whom are caring for disabled children) along with other supporters, will go to raise funds for us, from running marathons to climbing mountains, to baking cakes and holding coffee mornings. We are extremely grateful to them all for helping us to continue our vital work helping those affected by rare chromosome disorders. We were delighted by the response to our first fundraising appeal for two years, raising over £3,000 in one-off donations plus new regular giving.

One of the year's highlights was holding our first family conference weekend for 4 years. Attended by over 300 parents, children and professionals, it was made possible by funding from Jeans for Genes. Families attended workshops on a variety of relevant topics whilst the children were well cared for by a specialist crèche team. It was a great opportunity for family carers to meet others, relax and socialise in a non-judgmental environment whilst learning about rare chromosome disorders.

In East Anglia, we piloted the first, in what we hope will be a series of regional, nationwide events, combining training for our local volunteer contacts (of which we now have a network of over 200) with a social event for local families. Attended by over 100 parents, children affected by rare chromosome disorders and their siblings, it was an all-too-rare opportunity to meet and get to know others facing similar challenges. The children were entertained by a children's entertainer while their parents could relax. These events are key to alleviating the isolation felt by many of our families.

Our unusually high level of reserves reflect planned future expenditure. Plans include recruiting an Information Officer/Database Co-ordinator, the implementation of an upgraded database of members' chromosome disorders and the imminent launch of our new website.

Sophie Sainty, Chair of Trustees April 2013

Objects

Unique is the UK's only charity for families affected by rare chromosome disorders (RCDs). Each year many hundreds of babies are born with these disorders which are caused by them having parts of one or more of their chromosomes missing, added on or rearranged. Although collectively affecting at least 1 in 200 live-born babies, individually the disorders are very rare and remain poorly understood by many doctors and other health professionals. This leaves parents with many unanswered questions, feeling confused and lost.

We aim to beat the desperate isolation of those affected by providing them with information and support and by raising public awareness of the disorders and the demands they place on those affected and their families.

Specifically *Unique* offers:

- the only recognised **database/registry** to comprehensively document the in-depth natural histories of those living with rare chromosome disorders. Used by researchers and professionals worldwide to assist in their work, it extends beyond clinical information to include educational, social, behavioural and developmental data. *Unique's* Database is the only available and reliable resource for discovering the complex effects of new chromosome disorders on children over their lifetimes.
- our **Listening Ear telephone and email helpline service,** often the first point of contact for distressed parents of a recently diagnosed child and professionals needing information.
- our **Unique information project** which through research and evidence gathered from members has enabled us to produce over 140 chromosome disorder-specific information guides as well as guides to more generic topics relevant to and requested by our members
- our **family matching service**, linking those living with similar conditions to be able to share their experiences and information with others, thereby offering invaluable mutual support
- **study days, family conferences and social events** which bring together families and professionals to develop a better understanding and knowledge of specific disorders and the means to offer better support.
- our **specialist website** attracting just under 10,000 new visitors per week, which along with our regular **magazine**, provides a lifeline to many families.
- our **network of over 200 local volunteers** who can empathise with, and support families of, newly diagnosed children, signposting them to local services and much-needed resources.

Rare Chromosome Disorder Support Group

Report of the Trustees

For the year ended 31 March 2013

Strategic direction

Our three year operating plan for 2012-2015 focuses on consolidating previous work and developing frontline services (family support and publications). It also recognises the need to strengthen and expand *Unique* to meet the challenges posed by rapidly increasing demand for our core services.

Three areas are particularly important: further development of our database of case histories, increasing capacity in our information and family services and strengthening our fundraising efforts. Trustees will continually monitor progress in these areas through regular consultation with key staff.

Vision, mission, values

Vision
Unique's vision is of a world where all families who have a member with a chromosome disorder 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 chromosome disorder and to raise public awareness.

Aims and Objectives
1. Provide information and support to anyone affected by, and dealing with, chromosome disorders.
2. Relieve the isolation of those affected by a chromosome disorder.
3. Promote and participate in research.
4. Act as an umbrella organisation for all low-incidence chromosome disorders.

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. Below are 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 2012-13

In this section the significant activities undertaken during the past year and our achievements in relation to our stated objectives are grouped under the main strands of our work: our information project, family support services, providing a network for families and professionals and awareness-raising and collaboration.

Information project
- Our 142 guides to specific rare chromosome disorders include five brand new guides published this year. All are independently medically-verified and available free from our website or from Unique staff. They have been downloaded tens of thousands of times. No other organisation provides such a breadth of accessible, family-friendly literature, covering medical, behavioural and other issues relating to rare chromosome disorders.
- Four other brand new guides have been written and are currently being independently verified by expert geneticists who volunteer their time to assist us.

- A further five of our existing information guides have been substantially updated with new information gathered from our member families about their children.
- Volunteers have translated 17 more guides into various languages for those for whom English is not their mother tongue. We now have information guides in 11 languages, including Arabic, French, Spanish and Polish.
- We have further increased the capacity of our information team. Dr Catherine Whitlock, a freelance Science writer works with us on an *ad hoc* part-time basis, assisting the team with researching and writing our information guides.
- This year we have also published guides to more general topics requested by families, e.g. specialist grants, travel insurance and sensory toys. Feedback from family carers has included:

  "Our son is 8. We've never been abroad with him but the 'Holidays Short Breaks Travel Insurance' guide from Unique has given us the confidence to research a holiday abroad next year - which will give us a much needed break and give our son an opportunity to broaden his horizons - thank you."

As technology for diagnosing chromosome disorders becomes more sophisticated, we are experiencing substantially increased demand from families and professionals for information about much rarer disorders. Many require individually tailored responses from our information team, meaning their focus is increasingly shared between developing the guides and providing information about very rare disorders for which there is little or no information in the public domain.

Family support services, including our Listening Ear

Our Listening Ear telephone and email helpline is often the first point of contact for distressed parents and carers who have received a diagnosis of a rare chromosome disorder for their child. They often approach us with a great many questions, confused and worried about the future.

- Soaring demand for our services means that our Listening Ear team have again this year answered over 20,000 telephone and email queries. We continue to ensure that families are provided with information, support, signposting and understanding that is simply not available elsewhere.
- Our database of patients with chromosome disorders is crucial to providing our information and support to family carers, health professionals and researchers, information that only we can supply. Accurate, up-to-date data are essential and to this end during the year we continued the process of contacting all members to update their database entries with any new information.
- Our Family Support Officer has continued to support new and existing members with tips, guidance and details of a huge variety of resources to help them care for their disabled children. She also moderates our discussion groups on Facebook and other social networks which are becoming a lifeline for many families.
- We have produced a brand new awareness card to be carried by family carers to explain their child's condition and these have been given to over 230 carers to date. They tell us they have been used successfully in shops, restaurants, at theme parks and airports. They are particularly useful for members who have trouble queuing. One parent told us recently:

"J finds boarding aeroplanes stressful so I used the card at Heathrow, asking if we could priority board. My request was allowed and it was much easier as we were able to be sat and settled before the majority of passengers got on."

Providing a network for families and professionals

- We held our first family conference weekend for four years in April 2012. The event was a great success, attended by more than 300 family members, professionals and volunteers and was made possible due to funding from Jeans for Genes. Dr Evan Harris gave the keynote speech and delegates attended a variety of workshops given by professionals on topics relevant to RCDs. Geneticists from the West Midlands also hosted a hands-on genetic testing demonstration. There were opportunities for parents and carers to socialise and get to know others facing similar challenges and a crèche for children with rare chromosome disorders and their siblings.
- In March 2013, with funding from the PJK Charitable Trust we held our first Local Contacts Training/Family Social event in East Anglia. The day was split into two, with training for four of our local volunteer contacts in the morning, then a social event for local families in the afternoon. The children were kept amused by a children's entertainer while their parents could relax, get to know each other and swap tips and information. Following the success of this event we are aiming to roll it out to other areas.
- We continued to build and strengthen relationships with health and other involved professionals and have close links with specialists at Regional Genetics Centres across the country. Over 30 geneticists and other professionals gave up their time to be at our family conference weekend.
- Dr Jenny Hague, one of our Information Officers, works part-time as a paediatrician in the NHS, a role that helps us develop new ways to reach even more professionals.
- We work closely with other third sector organisations including Genetic Alliance UK, Rare Disease UK and SWAN UK.
- Our presence on various social networks goes from strength to strength, particularly our Facebook groups, linking members in their locality. This has encouraged people to meet and devise informal local support networks under the Unique umbrella.
- Our innovative approach is further enhanced by regular email bulletins, reaching thousands of interested parties and we have over 1,600 followers of our Twitter feed.

Awareness-Raising and Collaboration

Raising awareness of rare chromosome disorders, particularly among professionals, is a key objective. During the year our staff gave a number of presentations, manned awareness-raising stands at conferences and participated in various research projects. Highlights included:

- Working with a team from the University of Oxford to organise two study days with associated research for families affected by XYY and XXX syndromes.
- Our CEO sitting on professional advisory boards including the Wellcome Trust Sanger Decipher project and the Deciphering Developmental Delay (DDD) project.
- Hosting an awareness-raising stand at the British Society of Human Genetics conference.
- Presenting at the National Institute of Health Research (NIHR) workshop on 'Rare Diseases – The Patients' Perspective'.
- Giving teaching sessions to medical students at University College, London.

- Working 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.
- Participating in a Rare Disease UK stakeholder event on the Department of Health's rare disease plan.
- Presenting to the British Association of Childhood Disability annual meeting.

Challenges

In 2012-13 we again saw record growth in demand, with over 1,150 new members joining us, taking us to a total of almost 10,000. As diagnostic technology becomes ever more sophisticated and widely used, this will only continue. With rapidly increasing demand and a continuing uncertain economic climate we face a significant challenge: maintaining excellence in service provision whilst continuing to develop Unique with limited, finite resources. To this end we are focused on developing our fundraising to further diversify our income and are investing resources 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 the many people who gave up their time to support us, including:

- Over 200 Unique members who volunteer as local contacts, helping support members in their area by signposting them to local resources and services, holding social events such as coffee mornings and by just being there to listen.
- More than 30 geneticists, medical and other professionals who give up their time to check and verify our published information on a wide range of chromosome disorders.
- 20 volunteers involved in translating our information guides into other languages.
- Many others helping with activities such as IT, marketing and despatching merchandise.

Financial Review

In these uncertain times we continued to budget conservatively and control expenditure closely to ensure appropriate financial management. Trustees and key staff hold monthly Skype calls to discuss management accounts meaning any issues can be foreseen and dealt with quickly.

Income

Unique's income for 2012-13 is £308,799, an increase of 1.5% on 2011-12, the second consecutive year of income growth. Of this total, our unrestricted income from various trusts and foundations and from donations and fundraising from members, their friends, family and employers totalled £229,399. Unrestricted income 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 £44,550 and restricted income of £79,400 covering costs associated with the family conference weekend, other events and published information guides.

Expenditure
Total expenditure for the year was £274,626. Planned spending to strengthen our infrastructure (including establishing our first office base) and the cost of running our family conference weekend meant overall expenditure increased by 28% on the previous year but nevertheless was carefully controlled and remained within budget.

At £12,442, the ascribed value of donated services remained on a par with those reported in 2011-12. Throughout the year we continued to benefit from a Google Grant covering search engine advertising costs and a storage unit donated by Supastorage Ltd.

Reserves policy
The Trustees have decided to adopt a policy of holding a minimum reserve equivalent to four months' average actual core operating costs for the previous year (not including the value of donations in kind). At this level the Trustees feel that the charity would be able to continue to provide its core services. This policy is regularly reviewed on an on-going basis. The Trustees have budgeted for reserves for the year 2012-13 of not less than £87,500.

In addition to the minimum reserve, having worked hard to increase our income while at the same time budgeting prudently and carefully controlling our expenditure, reserves at the end of the year are at £275,731, with unrestricted reserves standing at £262,636. This means that we can safeguard key services and plan with confidence to meet the needs of an ever-growing number of families. Trustees have therefore decided to continue to designate £40,000 to protect the Listening Ear Telephone and Email helpline service. Restricted reserves of £13,095 consist predominantly of grants towards the salaries of our helpline and information officers.

Plans for the future
Our success in growing our income over the last two years means we have sufficient resources to continue investing in infrastructure and services of direct benefit to our members. Plans for the year include:

- Continuing the full upgrade of our database/registry of chromosome disorders 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 to strengthen our information team through the recruitment a new Information Officer/Database Curator, further improving the accurate recording and use of data provided by member families.
- Having successfully piloted an event, we plan to run two further local contacts training/family social events, in the West Midlands and North East. We will gather our local volunteer contacts from each area to meet the Unique staff team for training and support in their role. We will also bring together local families to meet and get to know others in their area living with RCDs and their local contacts to establish local support networks.

These developments are key to meeting our objectives of providing information and support and reducing the isolation felt by many of those affected by RCDs. We are also investigating the possibility of leasing larger offices to bring more staff under one roof, so that we can continue to develop our infrastructure and benefit from further operational efficiencies that this will bring.

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 employed on a full-time basis and five on a part-time basis. Craig Mitchell, Chief Operating Officer (COO), is also Company Secretary. We also 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 chromosome disorder irrespective of race, religion, sexuality, marital status or culture. We are an equal opportunity employer.

During the year our 5 part-time staff worked from home and regularly communicated via VOIP to minimise costs and our carbon footprint.

Management of risk

The major risks to which the charity could be exposed, as identified by trustees and senior staff, were considered and recorded in an updated risk register in 2012 with contingency plans in place 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 as well as at other times.

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 received data protection and gift aid training this year. All staff and trustees who come into contact with children as part of their roles undergo an enhanced CRB check.

Unique has an Internal Research and Ethics Committee (comprising the CEO, the Senior Information Officer, the Chief Medical Advisor, a trustee and an adult sibling of a member with a chromosome disorder) to appraise research proposals of professionals requesting Unique's approval.

Governance

The board of Trustee-Directors of the charity met regularly throughout the year with the senior management team face to face and by conference call to define strategy and monitor performance. At 31 March 2013 Unique has four Trustee-Directors with backgrounds in law, business and marketing. The board meets three times per year and holds monthly conference calls with key staff via Skype focusing primarily on financial performance, enabling a proactive reaction to any income changes.

We are actively seeking additional Trustees to complement the existing skill set of board members. Two potential Trustees have offered to join the board and at least one will be appointed early in the next financial year.

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.

Governance and management structures of the charity are kept under constant review to ensure optimal use of resources.

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 7 June 2013 and signed on their behalf by

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

Independent auditors' report

To the members of

Rare Chromosome Disorder Support Group

We have audited the financial statements of Rare Chromosome Disorder Support Group for the year ended 31 March 2013 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 2013 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Opinion on other matters prescribed by the Companies Act 2006

In our opinion the information given in the Trustees' Annual Report for the financial year for which the financial statements are prepared is consistent with the financial statements.

Independent auditors' report

To the members of

Rare Chromosome Disorder Support Group

Matters on which we are required to report by exception
We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

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

Date:

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

Rare Chromosome Disorder Support Group

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

For the year ended 31 March 2013

	Note	Restricted £	Unrestricted £	**2013 Total £**	2012 Total £
Incoming resources					
Incoming resources from generated funds:					
Voluntary income	2	14,100	127,281	**141,381**	173,978
Activities for generating funds	3	-	87,604	**87,604**	82,726
Investment income		-	1,942	**1,942**	1,347
Incoming resources from charitable activities:					
Family support services	4	43,000	3,560	**46,560**	22,500
Information services	5	22,300	9,012	**31,312**	23,558
Total incoming resources		79,400	229,399	**308,799**	304,109
Resources expended					
Costs of generating funds:					
Fundraising costs		-	47,957	**47,957**	38,384
Merchandise costs		-	1,397	**1,397**	1,326
Charitable activities:					
Family support services		48,135	85,157	**133,292**	99,296
Information services		16,931	58,988	**75,919**	59,213
Governance Costs		-	16,061	**16,061**	16,074
Total resources expended	6	65,066	209,560	**274,626**	214,293
Net incoming / (outgoing) resources before gains & transfers		14,334	19,839	**34,173**	89,816
Transfers between funds		(1,239)	1,239	**-**	-
Net movement in funds	7	13,095	21,078	**34,173**	89,816
Reconciliation of funds					
Total funds brought forward		-	241,558	**241,558**	151,742
Total funds carried forward		13,095	262,636	**275,731**	241,558

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

Rare Chromosome Disorder Support Group

Balance sheet

As at 31 March 2013

	Note	£	**2013** **£**	2012 £
Fixed assets				
Tangible fixed assets	10		**2,063**	2,847
Investments	11		**700**	700
			2,763	3,547
Current assets				
Stock	12	**1,140**		1,148
Debtors	13	**7,667**		11,162
Cash at bank and in hand		**273,403**		263,555
		282,210		275,865
Creditors: amounts due within 1 year	14	**9,242**		37,854
Net current assets			**272,968**	238,011
Net assets	15		**275,731**	241,558
Funds	16			
Restricted funds			**13,095**	-
Unrestricted funds:				
Designated funds			**40,000**	40,000
General funds			**222,636**	201,558
Total funds			**275,731**	241,558

Approved by the trustees on 7 June 2013 and signed on their behalf by

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

Rare Chromosome Disorder Support Group

Notes to the financial statements

For the year ended 31 March 2013

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 £	**2013 Total £**	2012 Total £
Grants > £5,000:				
The John Ellerman Foundation	-	25,000	**25,000**	25,000
Ernest Kleinwort Charitable Trust	5,000	-	**5,000**	-
Sylvia Adams Charitable Trust	-	10,000	**10,000**	-
DJH Charitable Trust	-	-	**-**	10,000
Smith & Williamson	-	-	**-**	10,000
Grants < £5,000	9,100	9,550	**18,650**	33,530
Donated goods / services *	-	12,442	**12,442**	15,394
General donations	-	36,846	**36,846**	32,773
Corporate donations	-	4,131	**4,131**	25,606
Gift aid	-	18,103	**18,103**	13,536
Give As You Earn (GAYE)	-	2,025	**2,025**	1,692
Overseas donations	-	8,468	**8,468**	5,657
Pyramids	-	716	**716**	790
Total voluntary income	14,100	127,281	**141,381**	173,978

* Donated services consist of the following:

	2013 £	2012 £
Google AdWords (free web advertising)	**10,994**	13,883
Storage facilities	**1,448**	1,511
Total donated services	**12,442**	15,394

3. Activities for generating funds

	Restricted £	Unrestricted £	**2013 Total £**	2012 Total £
Fundraising activities	-	81,297	**81,297**	79,736
Christmas card & merchandise sales	-	6,307	**6,307**	2,990
Total activities for generating funds	-	87,604	**87,604**	82,726

4. Family support services

	Restricted £	Unrestricted £	**2013 Total £**	2012 Total £
Grants > £5,000:				
Jeans for Genes	23,500	-	**23,500**	-
The Rank Foundation	12,500	-	**12,500**	12,500
29 May 1961 Charitable Trust	-	-	**-**	5,000
De Lazlo Foundation	-	-	**-**	5,000
Grants < £5,000	7,000	-	**7,000**	-
Conference income	-	2,810	**2,810**	-
Magazine revenues	-	750	**750**	-
Total family support services	43,000	3,560	**46,560**	22,500

5. Information services

	Restricted £	Unrestricted £	**2013 Total £**	2012 Total £
Grants > £5,000:				
The Rank Foundation	12,500	-	**12,500**	12,500
Grants < £5,000	9,800	-	**9,800**	11,058
Study days and support	-	8,744	**8,744**	-
Donations	-	268	**268**	-
Total information services	22,300	9,012	**31,312**	23,558

6. Total resources expended

		Fundraising costs £	Merchandise costs £	Family support services £	Information services £	Governance costs £	Support costs £	**2013 Total £**	2012 Total £
Staff costs (note 8)		9,750	-	8,715	19,481	-	117,762	**155,708**	148,035
Recruitment		-	-	-	-	119	-	**119**	-
Training		1,955	-	155	-	-	-	**2,110**	40
Volunteer services		130	14	-	-	-	-	**144**	-
Postage & distribution		1114	-	14,261	857	-	854	**17,086**	13,436
Printing & design		3994	1,358	12,063	875	-	1,500	**19,790**	13,213
Stationery		774	25	1,700	1,019	106	262	**3,886**	2,800
Subscriptions, licences & charges		6598	-	252	2,474	755	178	**10,257**	6,160
Travel & subsistence		150	-	929	2,482	276	210	**4,047**	2,532
Room hire & event costs		-	-	22,036	2,352	40	68	**24,496**	253
Equipment & software		-	-	292	20	60	678	**1,050**	792
Books & publications		-	-	27	-	-	46	**73**	199
Home office costs		4	-	1,918	340	163	2,950	**5,375**	3,516
Office rent		-	-	-	-	-	11,000	**11,000**	-
Website & database development		-	-	79	-	-	-	**79**	305
Advertising	*	-	-	-	-	-	10,994	**10,994**	13,883
Insurance		-	-	-	-	1,361	1,060	**2,421**	2,643
Audit & accountancy		-	-	-	-	3,000	-	**3,000**	3,525
Depreciation		-	-	-	-	-	1,480	**1,480**	1,425
Storage expenses	*	-	-	-	-	-	1,511	**1,511**	1,511
Miscellaneous costs		-	-	-	-	-	-	**-**	25
Sub-total		24,469	1,397	62,427	29,900	5,880	150,553	**274,626**	214,293
Allocation of support costs		23,488	-	70,865	46,019	10,181	(150,553)	-	-
Total resources expended		**47,957**	**1,397**	**133,292**	**75,919**	**16,061**	**-**	**274,626**	214,293

*** Advertising represents entirely donated services with no cost to Unique (see note 2). Storage expenses include donated services, with no cost to Unique, between April 2012 and February 2013 (see note 2).**

7. Net movement in funds

This is stated after charging:

	2013	2012
	£	£
Depreciation	**1,480**	1,425
Trustees' indemnity insurance	**1,361**	1,060
Trustees' reimbursed expenses	**Nil**	Nil
Auditors' remuneration:		
▪ Statutory audit (including VAT)	**3,000**	3,000
▪ Under-accrual in prior year	**-**	525

8. Staff costs and numbers

Staff costs were as follows:

	2013	2012
	£	£
Salaries and wages	**131,958**	125,626
Social security costs	**11,450**	11,485
Freelance staff	**12,300**	10,924
	155,708	148,035

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

	2013	2012
	No.	No.
Average number of employees (full-time equivalent)	**4.60**	4.50

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 2012	**9,587**
Additions in year	**696**
At 31 March 2013	**10,283**
Depreciation	
At 1 April 2012	**6,740**
Charge for the year	**1,480**
At 31 March 2013	**8,220**
Net Book Value	
At 31 March 2013	**2,063**
At 31 March 2012	2,847

11. Investments

	2013 **£**	2012 £
Artwork	**700**	700

A Tracey Emin 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 2013.

12. Stock

	2013 **£**	2012 £
Merchandise	**1,140**	1,148

13. Debtors

	2013	2012
	£	£
Trade debtors	**268**	-
Prepayments	**7,399**	5,539
Other debtors	**-**	5,623
	7,667	11,162

14. Creditors : amounts due within 1 year

	2013	2012
	£	£
Trade creditors	**2,795**	2,238
Accruals	**3,000**	3,100
Other taxation & social security	**3,447**	3,196
Deferred income	**-**	29,320
	9,242	37,854

15. Analysis of net assets between funds

	Restricted funds	Unrestricted funds	**Total funds**
	£	£	**£**
Tangible fixed assets	-	2,063	**2,063**
Investments	-	700	**700**
Current assets	13,095	269,115	**282,210**
Current liabilities	-	(9,242)	**(9,242)**
Net assets at 31 March 2013	**13,095**	**262,636**	**275,731**

16. Movements in funds

	At 1 April 2012 £	Incoming resources £	Outgoing resources £	Transfers between funds £	**At 31 March 2013 £**
Restricted funds					
Jeans for Genes	-	27,000	(22,159)	(4,841)	**-**
The PJK Charitable Trust	-	3,500	(2,948)	-	**552**
Rank Foundation	-	25,000	(16,261)	-	**8,739**
The Worshipful Company of Grocers	-	2,000	(1,000)	-	**1,000**
Annandale Charitable Trust	-	3,300	(3,300)	-	**-**
Skills For Care	-	4,500	(4,500)	-	**-**
Regional family funding	-	14,100	(14,898)	3,602	**2,804**
Total restricted	-	79,400	(65,066)	(1,239)	**13,095**
Unrestricted funds					
Designated funds:					
Listening Ear Fund	40,000	-	-	-	**40,000**
Total designated funds	40,000	-	-	-	**40,000**
General funds	201,558	229,399	(209,560)	1,239	**222,636**
Total unrestricted funds	241,558	229,399	(209,560)	1,239	**262,636**
Total funds	241,558	308,799	(274,626)	-	**275,731**

Purposes of restricted funds

Jeans for Genes	To fund the costs associated with the family conference weekend held in April 2012. The transfer to general funds represents initial setup costs incurred in the 2012 accounting period, which were paid from general funds. This was prior to receiving funding for the event.
The PJK Charitable Trust	To fund the costs associated with organising and holding a local contacts training and family social event in East Anglia in March 2013.
Rank Foundation	To fund the salary costs of information and helpline officers.
The Worshipful Company of Grocers	To fund the costs associated with producing an information guide to 'Next Generation Sequencing'.
Annandale Charitable Trust	To fund the costs associated with production of an information guide to a specific rare chromosome disorder.

16. Movements in funds (continued)

Skills For Care	To fund the costs associated with production of information guides to specialist grants, travel and sensory toys.
Regional family funding	Funding received for the support of families in specified geographical regions.

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.