Company no. 5460413
Charity no. 1110661

Rare Chromosome Disorder Support Group

Report and Financial Statements

31 March 2009

Rare Chromosome Disorder Support Group

Reference and Administrative Details

For The Year Ended 31 March 2009

Company Number	5460413	
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:	
	Edna Knight	(Founder, Life President)
	Eleanor Fiske	(Company Secretary)
	Gillian Manvell	(Acting Chairman)
	David Williams	
Principal Staff	Beverly Searle	Chief Executive Officer
	Craig Mitchell	Operations Manager (appointed 1 May 2008)
	Marion Mitchell	Family Support Officer
	Prisca Middlemiss	Senior Information Officer
	Sarah Wynn	Information Officer
	Satnam Juttla	Information Officer
	Julie Griffin	Finance & Fundraising Executive Officer
Chief Medical Advisor	Professor Maj Hulten	
Bankers	Charities Aid Foundation Kings Hill West Malling Kent ME19 4TA	Birmingham Midshires PO Box 81 Pendeford Business Park Wobaston Road Wolverhampton WV9 5HZ
Auditors	Godfrey Wilson Ltd Chartered Accountants & Registered Auditors Pike House George Street Nailsworth Gloucestershire GL6 0AG	

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2009

The trustees present their report and the audited financial statements for the year ended 31 March 2009.

During the year, the charity pursued plans to develop both infrastructure and services to accommodate the needs of a rapidly-increasing membership. At the same time and in common with other charities, Unique saw a fall in income necessitating a draw on reserves. Without significant fundraising successes, we believe that this trend could continue so a contingency budget has been set for 2009-10 to deliver family support services on a markedly reduced income. General funds have been designated to protect one core frontline project. We hope to avoid curtailing services; operational costs and income generation ef fectiveness are being monitored closely.

Unique is a UK charity specialising in supporting and informing families with chromosome disorders, both in the UK and internationally. It has built up a comprehensive database of the lifetime effects of very rare conditions.

New diagnostic techniques and advances in mapping the human genome mean increasing numbers of rare conditions are being recognised. These could account for a childôs learning difficulties or other mental and physical disabilities, as well as complex health issues, yet clinicians - and families - have little information on the implications of the disorders, in particular how they will affect their child in the long term.

Unique was founded in 1984 by a mother of children affected by a rare chromosome disorder (RCD). The organisation offers telephone and email support and provides family-friendly information through leaflets and a website. It connects families affected by the same conditions and also organises social events.

Unique has developed an accurate database of symptoms, health issues, behaviours and development over a lifetime in thousands of the most rare chromosome disorders. This helps families and clinicians to identify possible issues and enables them to understand the effects of the disorder on the childôs development.

Company Information

The Rare Chromosome Disorder Support Group, known as ôUniqueô, was founded and is led principally by the families of children and young people with rare chromosome disorders (RCDs) for the benefit of all people with RCDs. The leadership team is profoundly grateful for the support of the many other busy professionals who donate their experience, expertise and judgement to Unique in the interests of the charity and of its thousands of members around the world.

The Rare Chromosome Disorder Support Group, Unique, became a registered charity on 24 July 1993. The charity was incorporated on 24 May 2005 with company number 5460413. The company is registered as a charity with number 1110661. The company is limited by Guarantee; the amount guaranteed by each member is not in excess of £10 (ten sterling pounds).

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 ï Accounting and Reporting by Charities (issued in March 2005).

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2009

The charity, as an incorporated company, is governed by its Memorandum and Articles of Association. Each trustee is a director of the company and references to trustees include references to the same persons as directors.

The Objects of the Charity and how these are achieved

At least one in every 200 live-born babies is known to have a RCD. These disorders are individually rare but collectively numerous. Many cause severe physical and learning disabilities as well as complex health issues. The rate of detection of RCDs is increasing, as new methods of molecular analysis to identify cryptic chromosome abnormalities become commonplace.

The objects of the Charity are to reduce the isolation caused by a RCD diagnosis, by providing links and sharing information between affected families and improving public awareness of the effects of RCDs. The trustees confirm that they have referred to the Charity Commission's general guidance on public benefit when reviewing the Charity's aims and objectives, planning future activities and setting policy for the year.

Unique has become an expert partner organisation working worldwide with clinical geneticists to publish medically verified leaflets on hundreds of different RCDs, benefiting both its own members and the wider community. Publicity for Unique's successes raises the public profile of RCDs, particularly in the UK. Unique speaks to policy makers and decision takers on behalf of all its stakeholders and this responsibility is accepted with integrity. People with RCDs and their relatives are at the heart of Unique; the founding principle of improving life for all people affected by RCDs drives all the charity's activities.

On a day-to-day basis we provide telephone and email support and bespoke information to families and individuals with RCDs and to the professionals who work with them, including through the website www.rarechromo.org and the member magazine 'Unique'. We hold conferences and study days and provide speakers for medical and other organisations, raising awareness of the impact of an RCD on family life. Our ethics committee considers participation in research projects that could be of benefit to our members.

Trustees

It is the policy of Unique that a majority of trustees should have a family member with a RCD.

Trustees and Directors during the year

Edna Knight MBE (Founder, Life President)
Gillian Manvell (Acting Chairman)
Eleanor Fiske (Company Secretary)
David Williams

In December 2008, Unique's founder and Life President Edna Knight was presented with her MBE by Prince Charles. The honour recognised Edna's hard work and dedication over twenty-five years of supporting families and raising awareness of rare chromosome disorders.

Members of the Executive Committee during the year

Senior management team:
Beverly Searle (Chief Executive Officer - CEO)
Julie Griffin (Finance & Fundraising Executive Officer - FFEO)
Craig Mitchell (Operations Manager ï OM) - appointed 1 May 2008

Staff:
Prisca Middlemiss (Senior Information Officer - SIO)
Marion Mitchell (Family Support Officer)
Satnam Juttla (Information Officer)
Sarah Wynn (Information Officer)

Family representatives:
Carey Hunt
Lydia Dickie
Marie Layng

Chief medical adviser:
Professor Maj Hulten

In May 2008 the Trustees were pleased to appoint Craig Mitchell as the charityôs first Operations Manager. With a background in communications and HR, Craig has improved significant aspects of the charityôs infrastructure and facilitated Uniqueôs achievements this year. As well as providing an administrative platform for all activities, he played an active role in securing grants.

Structure, Governance and Management

Trustees are recruited by advertising through the membersô magazine, appropriate media and personal contacts. In 2008 the Board sought to identify additional trustees with professional experience in accountancy, charity fundraising, PR and marketing as well as those who could represent the perspective of families from a diverse range of ethnic backgrounds. New trustees are to be appointed in 2009-10.

Potential trustees are interviewed by one or more trustees and the CEO, who then make a recommendation to the Board. Prior to attending a trusteesô meeting, a new incumbent is provided with full documentation on the charityôs activities and plans and on his/her role and responsibilities as a trustee and company director. A new trustee may contact other Board members for more information.

The Board of trustee directors of the charity has met regularly with the senior management team: CEO, FFEO and OM, now extended to include the SIO: to define strategy and monitor performance.

An Executive Committee of trustees, staff, Chief Medical Officer and other family member representatives met twice during the year to receive and discuss reports on strategy and activities. The trustees delegate their responsibility for the day-to-day activities of the charity to the CEO, assisted by the FFEO and OM.

During the year, meeting minutes were recorded by Sarah Wynn and Gemma Mitchell. We thank both for their hard work.

The major risks to which the charity could be exposed, as identified by trustees and senior staff, were considered and recorded in an updated register in 2008 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.

A review of the governance and management structures of the charity will be completed in 2009. Trustees, managers and executive will ensure that governance structures are streamlined and efficient to provide the best interface for meeting the needs of members in a manner consistent with the Charity Commission's general guidance on public benefit.

Meanwhile, on behalf of Unique, the trustees wish to express publicly the enormous debt that is owed by the group to all past and present members of the Executive Committee. Since 1992, some family members of Unique have given up their Saturdays four times a year or more to travel and participate in committee meetings, taking part in discussions on policy, planning and group activities. Some became officers or joined the staff, others took on key roles at conferences or kept families informed about benefits and grants. The charity as it is today grew from the dedication of long-standing Executive Committee members and we all owe them our most sincere thanks.

Objectives and Activities

Unique has continued to follow and review the operating model detailed in the five-year operating plan 2006-2011 which clarified the charity's vision and aims, set its strategic direction and defined the operational parameters. The trustees confirm that they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the Charity's aims and objectives, planning future activities and setting policy for the year.

The key objectives of Unique remain:

- **Information and support**
- **Research and publication**
- **Umbrella organisation for all rare chromosome disorders**

The strategy to achieve these objectives in the timeframe of the operating plan is to:

- **Expand membership** – double membership without loss of high-quality personalised services
- **Publish more** – increase annual output of disorder information leaflets by 60%
- **Increase research participation** – from 6 to 20 appropriate projects annually
- **Increase awareness** – within all circles: medical, government, public, RCD families
- **Increase number of volunteers** – extend the number of worldwide local contacts from 135 to 160 and increase the number and range of other *ad hoc* volunteers.

To effect and maintain this strategy demands increased financial and staff resources and strong partnerships with other organisations. During 2008-9, Unique's trustees and staff focused on achieving operating stability and consolidation of infrastructure, growing simultaneously the specialist services team's ability to meet better the needs of an ever-increasing number of member families.

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2009

Activities

Unique is an international support charity whose core services include making challenging information both accessible and easily digestible, through dif ferent media, cost-ef fectively, on an ongoing basis.

The Information Project, Study Days, ôListening Earô Service and ôBeating The Isolationô Project are achievable solely from the confidential, comprehensive offline database which details the lifetime effects of specific chromosome disorders on individual members, providing a range, breadth and depth of information for new and existing members and professionals that is not available anywhere else in the world.

Unique aims to educate the general public about RCDs, generating funds through talks and presentations and using national and local media and social networking websites when appropriate. Unique seeks opportunities to educate policy-mak ers about RCDs and their ef fects on family life.

The rate of growth in new members has increased by 74% during the year, illustrated by the following statistics:

	31 March 2004	31 March 2005	31 March 2006	31 March 2007	31 March 2008	31 March 2009
Member families (cumulative) Year on year % change	4,000	4,500 +13%	4,920 +9%	5,350 +9%	5,800 +8%	6,583 +14%
New families Year on year % change	488	412 -16%	400 -3%	430 +8%	450 +5%	783 +74%
Total countries (cumulative)	64	65	68	69	73	76

A membership of over 6,500 member families represents well over 7,000 affected individuals with a RCD. The dramatic increase in the number of new families joining last year is due partly to substantial improvements in diagnostic techniques as well as the improved awareness of Unique among professionals and the use of new media and web publicity to heighten our profile generally. The rate of growth in new family memberships look s likely to continue to increase year on year.

Achievements and Performance

Highlights

- In February 2009, GlaxoSmithKline announced Unique to be one of ten winners of the 2009 GSK Health Impact Award, selected from 400 charity entrants. These prestigious awards are run in conjunction with the Kingôs Fund and this win was a great boost to our efforts to raise awareness as well as a valuable contribution to the costs of our work over the next year.

- Unique has been appointed one of six guest charities to benefit from the nationwide 2009 Jeans for Genes campaign.

These accolades, recognising the value of Unique in the field of genetics and health, are a tribute to the skills and dedication of our staff.

- In November 2008 the twelfth Unique family conference took place near Daventry. We welcomed 400 people from around the world. For many, this was their first Unique conference. Crèche staff, professionals and volunteers, looked after over one hundred children and young people with special needs to ensure that all families wishing to come, could come. Feedback indicated that this was our most successful conference to date.

- We have been successful on first application to a number of bodies, including:

  - **HONcode** Uniqueôs website met the standard required by the Health on the Net Foundationôs Code of Conduct (HONcode), providing reassurance for users that it is a reliable and credible source of health information.

  - **YouTube** Unique was accepted on YouTube's non-profit programme. Now the charity has its own 'Unique' channel on YouTube; this is an excellent way to raise awareness of rare chromosome disorders and to promote Unique ôs services.

  - **Google** Unique was awarded a Google grant, worth an estimated £20,000 in word search advertising, which has increased traffic to the website significantly. Anyone searching for information on specific chromosome disorders will receive Unique as a primary search result. This has given a significant boost to our efforts to ensure that everyone who needs our specialist support, gets it.

- Using some funding received from the Gatwick Airport Pantomime Society (GAPS), we held a pilot social event for the Beating The Isolation project. In March 2009, families from Surrey and Sussex met for an afternoonôs entertainment. Parents were able to share their experiences and build new friendships.

- In May 2008 we launched Unique Facebook and MySpace sites, aimed at attracting new members who search using social networks rather than through websites as well as maintaining the support of existing members and the wider Unique community of friends and families. By March 2009 we had 1,403 members on our Facebook ófanôpage, with a further 2,429 members linked to the Rare Chromosome Disorder Support Group ócauseôpage.

- Validation of the effectiveness of our activities was given by member families completing our first online survey, to help us monitor and evaluate current support services. Results confirmed the importance of Unique as a provider of information on specific disorders, linking families living with similar disorders, sharing membersô stories, continuing to develop the database of chromosome disorders, raising awareness of RCDs and maintaining a website. The overall rating for Uniqueôs current services was ógoodôto éexcellentô

- During 2008, we were delighted to have three distinguished professors join Unique as clinical patrons alongside our existing patron, Professor Albert Schinzel, from Switzerland. We look forward to working even more closely with Professor Dian Donnai from the UK, Professor Jean-Pierre Fryns from Belgium and Professor Judith Hall from Canada.

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2009

Ongoing performance - core activities

Magazine

We published three magazines during the year, allowing families and professionals to share their knowledge and experiences with other members. For many, this magazine is the 'face' of Unique. Over 1,850 member families receive the electronic version, saving the charity postage and printing costs and improving our carbon footprint.

In July 2008 we introduced a bi-monthly e-news alert, with over 2,500 subscribers. This allows us to keep friends of the group in touch with ways to support Unique as well as with our latest news.

Website: www.rarechromo.org

Our website attracts new members daily as well as worldwide interest from medical and other professionals. Since its launch, the website has received 800,000 new visits. Our family-friendly, medically-verified information leaflets on specific RCDs are available for download on the website. The current website offers a wealth of information, including ways to support the charity. Members can access a password-protected discussion forum and the magazine archive. A major re-design is under way to make navigation easier.

'Listening Ear' Support Service

The CEO, an Information Officer and the Family Support Officer staff the 24-hour 'Listening Ear' service, the initial point of contact for all new families and professional inquirers. Positive feedback from members and professionals confirms the value of this service. With two qualified geneticists on our staff, members are assured of reliable information on RCDs. During the year we received over 800 telephone enquiries and 20,000 email enquiries.

12th Unique Family Conference – November 2008

The main day of the 2008 family conference included plenary sessions on the UK's 'Every Disabled Child Matters' campaign and 'Positive Perspectives on Rare Chromosome Disorders'. Afternoon workshops covered Challenging Behaviour, Communication, Advice from Experienced Parents and Sex Chromosome Aneuploidies.

2007-8 grants totalling £12,000 were used to subsidise the conference, keeping registration and meal costs low for families.

Unique Database

The database is the core of all specialist support and information work. Using the database, staff provide professionals with anonymised information on the effects of a specific RCD, particularly valuable when there is no related Unique information leaflet. Feedback from professionals, especially geneticists and paediatricians, indicates that this service is invaluable for counselling affected families and managing their health and other needs.

As resources permit, we aim to send each registered member, every year, a copy of their own database entry to amend, update and approve. The great success in attracting new member families this year means that we have an urgent need for a database co-ordinator to manage the process.

Family Matching Service

Newly diagnosed families especially value the "family matching" service. By putting families in contact with each other, Unique reduces almost inevitable feelings of isolation and stress. Lifetime friendships arise through such contacts.

Information Project

A team of Unique Information Officers researches continuously and produces an extensive, ever-expanding range of family-friendly, medically-verified leaflets, reviewing and updating current leaflets as well as producing new material for families. More than 100 specific disorder leaflets are now available to download from the website.

Some leaflets are available in other languages such as French, German, Italian and Spanish, providing much-needed information for non-English speaking families. These foreign-language publications facilitate excellent working partnerships with other European support charities and clinical geneticists, extending the "pool" of families known to be affected by RCDs.

Study Days

As part of our commitment to the support of high quality medical research, Unique held two Study Days for families affected by sex chromosome trisomies. The first welcomed families whose daughters have XXX syndrome, the other, those whose sons have XYY syndrome. Both conditions can be difficult for families to deal with and there is little syndrome-specific help available. Families met clinicians and researchers from the Universities of Oxford and Reading and from the Wessex Regional Genetics Laboratory and genetics service, to exchange information about the syndromes and about the Sex Chromosome Trisomy research project.

Indirect Family Support delivered via Professionals

Unique strives to inform a wide range of professionals and colleagues in other support charities about the information and support we offer when a family's RCD is newly diagnosed. Over the past year we have continued to:

- give presentations to professionals and medical students;
- contribute as expert patient representative on professional committees and working charity advisory panels; and
- staff an awareness-raising stand at the annual conference of the British Society of Human Genetics. Three members of the Unique team are invited members of the BSHG.

Awareness-Raising

Unique runs a network of 135 UK and overseas "local contacts" who distribute the charity's RCD publicity posters and information leaflets to hospitals, social care departments, doctors' surgeries and special schools.

Unique is listed on innumerable public information databases and the charity has established good working relationships with a wide range of organisations such as Contact a Family (CaF), the Genetic Interest Group (GIG) and the Sanger Institute's DECIPHER project, a database of submicroscopic chromosomal imbalances. Such organisations refer families and individuals affected by RCDs to Unique.

Trustees' summary

The Trustees are delighted with the quality and quantity of family support services provided by Unique's staff. Both directly, through bespoke contact and materials and indirectly, through the family matching service and education of a wide range of healthcare professionals, the value and reputation of Unique continue to grow.

We wish to thank the CEO, her management team and all staff for their diligent delivery of services this year and for their tremendous efforts in continuing to promote the charity through all the means outlined above. Unique's team achieves the nigh impossible: the delivery of an ever-increasing volume of services without diminishing their quality.

The 2008 conference was a major success, to attract three new Unique patrons of the calibre of Professors Donnai, Fryns and Hall is a tribute to the team and the expansion of the charity's online presence into new media channels will be of major public benefit.

Finally, our success in securing a 2009 GSK Health Impact Award and the association with a high-profile media campaign such as Jeans for Genes testify to the efforts of Unique's CEO to keep the role, purpose and contribution of the charity in the spotlight.

Financial Review

Since Unique receives no guaranteed income from statutory sources, our income is inherently uncertain. Our primary source of unrestricted income has been donations, fundraising and matched-funding received from or generated by our members, their friends, family and employers. We are very grateful to all for their generous contributions, especially in this deteriorating economic climate.

Over the last year there has been a tension caused by the rapidly-increasing demand for family services coupled with a fall in income from all sources except donated services. We must entertain the possibility that both these trends will continue over the coming period.

In response, we have redoubled our efforts to secure new sources of revenue. The employment of a part-time specialist fundraiser is part of this strategy and her effectiveness will be monitored closely. Some new initiatives have begun, for example, a Charity Lottery scheme and the request made to members for an annual voluntary donation of £35 towards core costs.

Secondly, we produced a budget for 2009-10 assuming a sizeable drop in annual income but aimed at continuing to deliver all family support services, albeit in a reduced manner. There was no conference planned for 2009. Should we experience this further fall in income in 2009-10, our contingency position to safeguard core charitable activities would be to reduce reserves by up to 50% by year-end (see Reserves Policy). In this case, Unique would have to reduce some of its specialist activities by April 2010 as we could no longer afford to pay for the current number of staff hours.

As a precautionary measure, we designated £35,000 from general funds towards the ôListening Earô project for 2009-10 to provide protection for this vital service. Although this has reduced our free reserves, the designated funds will be spent during the coming financial year and at the same time, our projections for 2009-10 complement the fall in reserves with a 30% reduction in monthly expenditure.

In addition to detailed monthly management accounts, Unique carries out a robust financial review before each quarterôs meeting between trustees and the senior management team, when annual budgets are re-forecast in the light of up-to-date information. In this way any potential problems can be highlighted before they arise and policies revised appropriately.

Since the charity always has given superb value for money through the quantity and quality of its services delivered by highly-motivated staff, the trustees will pursue all avenues with vigour to ensure that Unique continues to develop to meet the increasing demand from newly-diagnosed families and from the professionals who are tasked to support them. The needs of all people affected by and working with RCDs now and in the future are too significant to allow Uniqueôs work to slow down or stall.

Investments

Unique owns a signed Tracey Emin print, ñLittle Familyò, donated by the artist herself. The etching has a reserve value of £700; an identical print sold at online charity auction in 2007-8 for considerably more.

To maximise interest income from our reserves during the year, £130,000 was invested in a Fixed Term Deposit on a three-month rolling term. At maturity in November 2008, the decision was taken to invest no more than £50,000 in any one financial institution to protect the charityôs reserves from institutional failure. Investment of reserves is kept under constant review to ensure optimal returns.

Expenditure

Costs associated with core family services have been contained. Any increases are in line with the increased membership, extra staff member, more content in the triannual membersô magazine and related postage costs. Website and helpline running costs are managed efficiently with additional voluntary support. Resources used to support families indirectly via professional contacts are within budget. Using the extraordinary RBS income from 2006-7, we built up our services and expanded the information and support going to professionals serving the RCD community.

Trustees' summary

The trustees would like to record their thanks to the Finance & Fundraising Executive Officer for her timely compilation of monthly management accounts and diligent approach to all tasks. In a year of increasing economic hardship for many families and donors, the charity managed its finances with due care and oversight, accommodating both reduced fundraising revenues and planned increases in fixed and discretionary costs (i.e. the appointment of an Operations Manager and the organisation of the twelfth family conference).

Reserves Policy

During the past financial year, against a fall in income revenues, the charity dipped heavily into its general funds to finance planned expenditure. The trustees also resolved to designate £35,000 of unrestricted funds for the 'Listening Ear' project in 2009-10. This sum will safeguard Unique's ability to respond to all inquiries from first-time callers in the coming year, albeit at a reduced level without further new investment. At 31 March 2009, therefore, free reserves had fallen by some £123,000 to £81,542, representing 3.5 months' running costs at the 2008-9 level (5 months at the forecast 2009-10 contingency level), in line with the policy of keeping 3 to 6 months' expenditure on deposit for emergencies.

Since year-end, however, and in the face of continuing uncertain global economic conditions and their negative impact on third sector funding, the trustees have adopted a revised reserves policy. Provided that the primary need to protect services to member families during the year is always recognised, then the new policy allows flexibility for using reserves to cover fluctuations in income. At all times, reserves should be kept at a level sufficient to meet the charity's contractual liabilities, maintain or replace essential equipment, provide working capital and ensure that the charity can continue to provide stable, high-quality services. At the time of writing this report, from forecasts for 2009-10, the trustees anticipate a need to draw again on free reserves (see Financial Review).

Gifts in Kind

With limited funding, Unique relies heavily on the generosity of individuals who contribute their professional expertise free of charge. The trustees wish to record their sincere thanks to all these generous supporters and to mention particularly the following individuals:

- Trevor Searle, for the comprehensive expertise and time he has dedicated over the past fourteen years, and continues to dedicate, to Unique's own database, website and online capabilities.
- Patrick Griffin, for his expertise and the time spent supporting staff with their ICT.
- Professor Maj Hulten, who spends countless hours checking and verifying Unique's publications on specific disorders. Over the years, Maj has brought the perspective of a professional geneticist to the executive committee.
- Other expert medical professionals around the world who verify and translate Unique's publications, offering advice and expertise willingly and with great enthusiasm.
- Carey Hunt, member of the executive committee, who provides her professional creative skills to design the excellent Unique publications.
- Sarah Clifton and Melissa Sheard, charity fundraisers, who provided professional guidance on fundraising strategy and grant application techniques.
- Local contacts, other group members, their families, friends and work colleagues; all those who volunteer their free time and energy to raise funds for the group.

Plans for the Future

The trustees' plans for the charity's immediate future include:

- continuing the core provision of support for families affected by RCDs, in order to relieve their feelings of isolation and despair.
- expanding services, as resources permit, to meet the growing annual demand from both existing members and new members, including those from communities that are hard to reach (due to cultural, religious, economic and/or language barriers).
- continuing to develop core services, increasing income to permit an expansion of these while reducing dependency on the goodwill of existing staff who work long hours voluntarily beyond their hours of paid employment to ensure that members' needs are met optimally.
- implementing the charity's five-year operating plan to achieve these goals.

25th Anniversary – Friends of Unique and the Silver Celebration Children's Appeal

In 2009 Unique celebrates its 25th anniversary. To mark this milestone, trustees have consulted members and well-wishers who wish to formalise a 'Friends of Unique' group. The embryonic 'Friends' would be tasked with running a 'Silver Celebration Children's Appeal' to really boost Unique's ability to achieve its aims - such as the doubling of UK membership by 2011, developing its family and professional support services by recruiting and training more highly-motivated staff and stepping up the rollout of the 'Beating The Isolation' project and other developments at local level. The aim of the Appeal is to raise £250,000 in 25 months and to meet this ambitious target will demand a well-honed strategy and energetic, sustained input. Trustees and staff are working with enthusiastic supporters to progress this project.

Fundraising

During the year 2008-9 Unique received two days' consultancy from the Charities Aid Foundation as part of our 2006-7 RBS award which, alongside professional advice donated by charity fundraisers, facilitated the development of a robust fundraising programme. This activity will be pursued vigorously in 2009-10, facilitated by our part-time fundraiser working on applications to trusts and foundations.

Service expansion

We wish to broaden what we can offer to our more mature young members. There can be no expansion, however, unless we can be sure of maintaining a high quality, personalised response to each and every inquiry. This is what Unique is known for and why the charity is valued so highly.

As trustees, it is our aim during the coming year to further develop a sound infrastructure, underpinning growth and assuring continued quality. We would like, too, to see 'Beating The Isolation' and other initiatives rolled out but this will depend upon our success in raising development funds. With at least one in 200 of the general population likely to be affected by a rare chromosome disorder, pressure on Unique's services will be unremitting. It is our role to ensure that the charity can continue to welcome everybody faced with such a devastating diagnosis, providing the informed friendship that families will need for decades to come.

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2009

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 group and charity and the incoming resources and application of resources, including the net income or expenditure, of the group 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 group and charity and which enable them to ensure that the financial statements comply with the Companies Act 1985. The trustees are also responsible for safeguarding the assets of the group and 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 the charitable company's auditors during the year and have expressed their willingness to continue in that capacity.

Approved by the trustees on and signed on their behalf by

E. M. Knight

Edna Knight - trustee (Life President)

Gillian Manvell - trustee (Acting Chairman)

Independent Auditors' Report

To The Members of

Rare Chromosome Disorder Support Group

We have audited the financial statements of the Rare Chromosome Disorder Support Group for the period ended 31 March 2009 which comprise the statement of financial activities, balance sheet and related notes. These financial statements have been prepared in accordance with the accounting policies set out therein and the requirements of Statement of Recommended Practice: Accounting and Reporting by Charities (issued in March 2005).

This report is made solely to the charitable company's members, as a body, in accordance with section 235 of the Companies Act 1985. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditors' 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 charitable company and the charitable company'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

The trustees (who are also directors of charitable company for the purposes of company law) are responsible for preparing the annual report and the financial statements in accordance with applicable law, United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and the Statement of Recommended Practice: Accounting and Reporting by Charities (issued in March 2005). The responsibilities of the trustees are set out in the statement of responsibilities of the trustees.

Our responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and International Standards on Auditing (UK and Ireland).

We report to you our opinion as to whether the financial statements give a true and fair view and are properly prepared in accordance with the Companies Act 1985. We report to you whether, in our opinion, the information given in the trustees' report is consistent with the financial statements. We also report to you if the charitable company has not kept proper accounting records, if we have not received all the information and explanations we require for our audit, or if information specified by law regarding the trustees' remuneration and other transactions is not disclosed.

We read other information contained in the annual report, and consider whether it is consistent with the audited financial statements. This other information comprises only the report of the trustees. We consider the implications for our report if we become aware of any apparent misstatements or material inconsistencies with the financial statements. Our responsibilities do not extend to any other information.

Basis of Opinion

We conducted our audit in accordance with International Standards on Auditing (UK and Ireland) issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgements made by the trustees in the preparation of financial statements, and of whether the accounting policies are appropriate to the charitable company's circumstances, consistently applied and adequately disclosed.

Independent Auditors' Report

To The Members of

Rare Chromosome Disorder Support Group

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements.

Opinion
In our opinion:

- the financial statements give a true and fair view, in accordance with United Kingdom Generally Accepted Accounting Practice as modified by the Statement of Recommended Practice: Accounting and Reporting by Charities (issued in March 2005), of the charitable company's state of affairs as at 31 March 2009 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;

- the financial statements have been properly prepared in accordance with the Companies Act 1985; and

- the information given in the trustees' report is consistent with the financial statements.

Godfrey Wilson Limited

Date: 19 May 2009

GODFREY WILSON LIMITED
Chartered Accountants &
Registered Auditors
Pike House
George Street
Nailsworth
Gloucestershire
GL6 0AG

Rare Chromosome Disorder Support Group

Statement of Financial Activities *(Incorporating an Income and Expenditure Account)*

For The Year Ended 31 March 2009

	Note	Restricted £	Unrestricted £	**2009 Total £**	2008 Total £
Incoming Resources					
Incoming Resources from Generated Funds:					
Voluntary Income	2	-	80,995	**80,995**	88,114
Activities For Generating Funds	3	-	59,294	**59,294**	82,992
Investment Income		-	8,364	**8,364**	10,643
Incoming Resources from Charitable Activities:					
Family Support Services	4	30,529	7,020	**37,549**	15,670
Total Incoming Resources		30,529	155,673	**186,202**	197,419
Resources Expended					
Costs of Generating Funds:					
Fundraising Costs		-	34,730	**34,730**	18,180
Merchandise Costs		-	3,526	**3,526**	3,399
Charitable Activities:					
Family Support Services		34,771	179,329	**214,100**	158,434
Governance Costs		-	23,858	**23,858**	17,479
Total Resources Expended	5	34,771	241,443	**276,214**	197,492
Net Incoming Resources Before Gains & Transfers		(4,242)	(85,770)	**(90,012)**	(73)
Transfers Between Funds		2,848	(2,848)	**-**	-
Net Movement in Funds	6	(1,394)	(88,618)	**(90,012)**	(73)
Reconciliation of Funds					
Total Funds Brought Forward		4,846	207,453	**212,299**	212,372
Total Funds Carried Forward		3,452	118,835	**122,287**	212,299

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 15 to the accounts.

Rare Chromosome Disorder Support Group

Balance Sheet

31 March 2009

	Note	£	2009 £	2008 £
Fixed Assets				
Tangible Fixed Assets	9		**1,593**	1,997
Investments	10		**700**	700
			2,293	2,697
Current Assets				
Stock	11	**1,970**		1,453
Debtors	12	**12,156**		6,693
Cash at Bank and in Hand		**112,275**		205,962
		126,401		214,108
Creditors: Amounts Due Within 1 Year	13	**6,407**		4,506
Net Current Assets			**119,994**	209,602
Net Assets	14		**122,287**	212,299
Funds	15			
Restricted Funds			**3,452**	4,846
Unrestricted Funds:				
Designated Funds			**35,000**	-
General Funds			**83,835**	207,453
Total Funds			**122,287**	212,299

Approved by the trustees on and signed on their behalf by

E. M. Knight

Edna Knight - trustee (Life President)

Gillian Manvell - trustee (Acting Chairman)

Rare Chromosome Disorder Support Group

Notes to The Financial Statements

For The Year Ended 31 March 2009

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 1985. 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 recov ered.

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 f ollows:

Computer equipment	4 years

Items of equipment are capitalised where the purchase price exceeds £500.

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

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

h) 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.

2. Voluntary Income

	Restricted £	Unrestricted £	**2009 Total £**	2008 Total £
Grants > £1,000				
Health Foundation	-	6,825	**6,825**	9,100
Royal Bank of Scotland Charitable Trust	-	-	**-**	10,000
Waterloo Foundation	-	-	**-**	5,000
Creating Chances	-	-	**-**	2,000
Reuben Foundation	-	-	**-**	100
Grants < £1,000	-	500	**500**	-
Donated Goods / Services *	-	31,045	**31,045**	18,640
General Donations	-	16,394	**16,394**	17,719
Corporate Donations	-	12,121	**12,121**	11,368
Gift Aid	-	8,921	**8,921**	10,325
Give As You Earn	-	1,827	**1,827**	2,488
Overseas Donations	-	2,729	**2,729**	839
Pyramids	-	633	**633**	535
Total Voluntary Income	-	80,995	**80,995**	88,114

* Donated services consist of the following:	**2009 Total £**	2008 Total £
Google AdWords (free web advertising)	**5,660**	-
Website & database design, development & maintenance	**6,000**	9,240
Professional verification of information in the charity's publications	**12,740**	5,200
Translation of charity's publications	**2,925**	-
Creche services	**1,200**	-
Professional fundraising services	**900**	-
Secretarial services	**300**	-
IT support	**1,320**	4,200
Total Donated Services	**31,045**	18,640

3. Activities For Generating Funds

	Restricted £	Unrestricted £	**2009 Total £**	2008 Total £
Fundraising Activities	-	54,188	**54,188**	80,049
Christmas Card & Merchandise Sales	-	5,106	**5,106**	2,943
Total Activities For Generating Funds	-	59,294	**59,294**	82,992

4. Incoming Resources From Charitable Activities

	Restricted £	Unrestricted £	**2009 Total £**	2008 Total £
Family Support Services:				
Charles Hayward Foundation	10,000	-	**10,000**	10,000
VICTA	5,950	-	**5,950**	4,828
ACT Training Grants	319	-	**319**	-
Anonymous	1,000	-	**1,000**	-
Steel Charitable Trust	1,000	-	**1,000**	-
Gatwick Airport Pantomime Society	8,500	-	**8,500**	-
University of Oxford	-	416	**416**	842
K U Leuven R&D - Eurogentest	513	-	**513**	-
Donations	2,967	-	**2,967**	-
Fundraising Activities	280	-	**280**	-
Conference Income	-	6,604	**6,604**	-
Total Family Support Services	30,529	7,020	**37,549**	15,670

5. Total Resources Expended

	----------Family Support Services----------										
	Fundraising Costs £	Merchandise Costs £	Magazine, Website, Helpline & Conference £	Database £	Information Project £	Beating The Isolation £	Indirect Family Support £	Governance Costs £	Support Costs £	**2009 Total £**	2008 Total £
Staff Costs (Note 7)	18,607	-	45,352	11,799	35,440	6,769	7,944	17,040	-	**142,951**	103,665
Training	323	-	282	-	-	-	40	-	-	**645**	-
Postage & Distribution	33	-	17,339	239	814	14	22	-	1,931	**20,392**	23,862
Printing & Design	988	3,526	13,689	39	956	141	1,647	-	1,206	**22,192**	19,738
Stationery	-	-	970	-	468	-	15	-	2,849	**4,302**	4,275
Subscriptions, Licences & Charges	8,776	-	-	-	10	-	406	50	1,459	**10,701**	7,339
Travel & Subsistence	1,484	-	1,286	18	197	14	1,489	814	802	**6,104**	4,618
Room Hire & Event Costs	207	-	21,299	-	951	2,281	-	645	8	**25,391**	1,863
Equipment & Software	-	-	-	-	163	1,392	-	359	864	**2,778**	2,278
Books & Publications	50	-	-	-	-	-	-	-	50	**100**	832
Telephone & Internet	48	-	160	-	168	-	-	-	2,890	**3,266**	2,197
Premises Overheads	-	-	-	-	-	-	-	-	694	**694**	528
Conference Costs	-	-	234	-	-	-	-	-	-	**234**	695
Website & Database	-	-	4,644	1,800	-	-	-	-	-	**6,444**	9,673
Advertising	-	-	5,660	-	-	-	-	-	-	**5,660**	-
Insurance	-	-	-	-	305	-	-	2,332	-	**2,637**	2,758
Audit & Accountancy	-	-	-	-	-	-	200	2,618	-	**2,818**	2,673
Consultancy	900	-	1,200	-	15,665	-	120	-	-	**17,885**	9,400
Depreciation	-	-	-	-	-	-	-	-	880	**880**	1,098
Miscellaneous Costs	-	-	-	-	101	-	-	-	39	**140**	-
Sub-Total	31,416	3,526	112,115	13,895	55,238	10,611	11,883	23,858	13,672	**276,214**	197,492
Allocation of Support Costs	3,314	-	2,541	2,360	2,360	737	2,360	-	(13,672)	-	-
Total Resources Expended	**34,730**	**3,526**	**114,656**	**16,255**	**57,598**	**11,348**	**14,243**	**23,858**	**-**	**276,214**	197,492

6. Net Movement in Funds

This is stated after charging:

	2009	2008
	£	£
Depreciation	**880**	1,098
Trustees' indemnity insurance	**1,321**	1,477
Trustees' reimbursed expenses	**102**	163
Auditors' remuneration:		
▪ Statutory Audit	**2,587**	2,350
▪ Grant Audits	**231**	323

7. Staff Costs and Numbers

Staff costs were as follows:

	2009	2008
	£	£
Salaries and Wages	**129,972**	93,816
Social Security Costs	**11,843**	8,515
Freelance Staff	**1,136**	1,334
	142,951	103,665

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

	2009	2008
	No.	No.
Average number of employees (full-time equivalent)	**4.97**	3.97

8. Taxation

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

9. Tangible Fixed Assets

	Total £
Cost	
At 1 April 2008	**4,394**
Additions in year	**476**
At 31 March 2009	**4,870**
Depreciation	
At 1 April 2008	**2,397**
Charge for the year	**880**
At 31 March 2009	**3,277**
Net Book Value	
At 31 March 2009	**1,593**
At 31 March 2008	1,997

10. Investments

	2009 **£**	2008 £
Artwork	**700**	700

During 2005 Tracey Emin donated 2 pictures to the charity. One was sold in 2006/7. The trustees have no immediate plans to sell the remaining picture, consequently it has been reported as a fixed asset investment in the accounts. Two professional valuations have been obtained and the picture has been included in the accounts at the average of these valuations.

11. Stock

	2009 **£**	2008 £
Merchandise	**1,970**	1,453

12. Debtors

	2009	2008
	£	£
Prepayments	**7,531**	6,280
Other Debtors	**4,625**	413
	12,156	6,693

13. Creditors : Amounts Due Within 1 Year

	2009	2008
	£	£
Accruals	**3,324**	2,350
Other Taxation & Social Security	**3,083**	2,156
	6,407	4,506

14. Analysis of Net Assets Between Funds

	Restricted Funds	Unrestricted Funds	**Total Funds**
	£	£	**£**
Tangible Fixed Assets	-	1,593	**1,593**
Investments	-	700	**700**
Current Assets	3,552	122,849	**126,401**
Current Liabilities	(100)	(6,307)	**(6,407)**
Net Assets at 31 March 2009	**3,452**	**118,835**	**122,287**

15. Movements in Funds

	At 1 April 2008 £	Incoming Resources £	Outgoing Resources £	Transfers Between Funds £	**At 31 March 2009 £**
Restricted Funds					
Charles Hayward Foundation	-	10,000	(10,000)	-	**-**
VICTA	-	5,950	(5,950)	-	**-**
SAFE Fund	2,862	-	(1,728)	-	**1,134**
Eurogentest Fund	1,984	513	(179)	-	**2,318**
Training	-	319	(319)	-	**-**
Magazine	-	585	(585)	-	**-**
Helpline	-	2,299	(2,299)	-	**-**
Information Project	-	2,363	(2,363)	-	**-**
Beating The Isolation	-	8,500	(11,348)	2,848	**-**
Total Restricted Funds	4,846	30,529	(34,771)	2,848	**3,452**
Unrestricted Funds					
Designated Funds:					
Listening Ear Fund	-	-	-	35,000	**35,000**
Total Designated Funds	-	-	-	35,000	**35,000**
General Funds	207,453	155,673	(241,443)	(37,848)	**83,835**
Total Unrestricted Funds	207,453	155,673	(241,443)	(2,848)	**118,835**
Total Funds	212,299	186,202	(276,214)	-	**122,287**

Purposes of Restricted Funds

Charles Hayward Foundation	To fund part of the Information Officer's salary
VICTA	To fund part of the Family Support Officer's salary
SAFE Fund	To fund all costs associated with the SAFE project
Eurogentest Fund	To fund all costs associated with the Eurogentest project
Training	To fund staff training
Magazine	To fund the costs of the magazine
Helpline	To fund the costs of the helpline
Information Project	To fund the information project

Purposes of Restricted Funds (continued)

Beating The Isolation	To fund extraordinary family support services related to piloting the BTI initiative in the Surrey and West Sussex region

Purpose of Designated Fund

Listening Ear Fund	The trustees have designated £35,000 from general funds to the charity's 'Listening Ear' project. This sum will ensure that the Unique helpline, a frontline service providing expert response to first-time callers from the UK and around the world, will be staffed appropriately for at least part of each UK working day during 2009-10. It is hoped that with matched-funding from a sponsor, the service can be developed further through the recruitment and training of additional staff and enhancement of current ICT capability.