

Rare Chromosome Disorder Support Group

Reference and Administrative Details

For The Year Ended 31 March 2007

| | | | | | | | | | |
|--------------------------|---|----------------|-------------------------|-----------------|------------------------|-------------------|---------------------|---------------|---|
| 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 Eleanor Fiske Gillian Manvell Michael Patterson (resigned 7 July 2006) | | | | | | | | |
| Principal Staff | <table><tr><td>Beverly Searle</td><td>Chief Executive Officer</td></tr><tr><td>Marion Mitchell</td><td>Family Support Officer</td></tr><tr><td>Prisca Middlemiss</td><td>Information Officer</td></tr><tr><td>Julie Griffin</td><td>Finance & Fundraising Executive Officer</td></tr></table> | Beverly Searle | Chief Executive Officer | Marion Mitchell | Family Support Officer | Prisca Middlemiss | Information Officer | Julie Griffin | Finance & Fundraising Executive Officer |
| Beverly Searle | Chief Executive Officer | | | | | | | | |
| Marion Mitchell | Family Support Officer | | | | | | | | |
| Prisca Middlemiss | Information Officer | | | | | | | | |
| Julie Griffin | Finance & Fundraising Executive Officer | | | | | | | | |
| Medical Advisor | Professor Maj Hulten | | | | | | | | |
| Bankers | Charities Aid Foundation Kings Hill West Malling Kent ME19 4TA | | | | | | | | |
| 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 2007

The trustees present their report and the audited financial statements for the year ended 31 March 2007.

Reference and administrative information set out on page 1 forms part of this report. The financial statements comply with current statutory requirements, the memorandum and articles of association and the Statement of Recommended Practice - Accounting and Reporting by Charities (issued in March 2005).

Structure, Governance and Management

Governing Document

The Rare Chromosome Disorder Support Group, also known as "Unique", became a registered charity on 24 July 1993, charity number 1024624. On 24 May 2005, The Rare Chromosome Disorder Support Group converted to a company limited by guarantee and was registered as a charitable company on 1 August 2005.

Recruitment and Appointment of Management Committee

The company directors are also charity trustees for the purpose of charity law and are responsible for the overall governance of the charity. Trustees are either named within the constitution or are elected.

The committee was delighted to welcome Lydia Dickie as a committee member as her period of employment with Unique came to end in August 2006.

Organisational Structure

Unique has three trustees and a management committee of six members (including trustees) which meets with staff and the charity's chief medical advisor at least four times a year to review the group's work and formulate strategy. Unique also benefits from the services of medical and other professional advisors who liaise with the charity's employees.

The charity benefits from the donated services of members who use their professional skills and knowledge to assist the group in areas including ICT, fundraising, marketing, creative design, copywriting, HR, consulting and legal advice as well as with general administrative support. The Chief Executive Officer ("CEO") is responsible to the management committee for the day to day operations of the charity and implements policies agreed by the board of trustees. The Finance & Fundraising Executive Officer assists the CEO in financial matters.

Recruitment and Appointment of Staff

Four members of staff were in the employ of Unique at year end, one full-time and three part-time. A fifth member of staff had been funded by a Children in Need grant which came to an end in August 2006.

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2007

Risk Management

A risk register is maintained to identify and monitor implications for the charity should its main strategic goals not be achieved or operating conditions change. The register is under review, with contingency plans to deal with challenges that might arise.

The response from families and professionals to the work of Unique is logged and reviewed continuously. Feedback arrives by letter, telephone, email and via the private members' forum of the Unique website or through information submitted for publication in the charity's magazine. The website www.rarechromo.org has been redesigned to encourage feedback from members of the public. The introductory pack sent to new inquirers contains a basic evaluation form and service guide sheets. More detailed evaluation forms are included with other appropriate correspondence and in conference and study day packs. The direction of future work is influenced by feedback from members.

Objectives and Activities

Objects

Unique aims to provide links between families whose children have similar clinical and/or practical problems caused by rare chromosome disorders. A rare chromosome disorder causing disabilities and health problems can occur in at least one in every 1,000 live births. The overall figure for any rare chromosome disorder (including balanced rearrangements that do not cause disability and ill health) is at least one in 200 live births.

Unique aims to raise awareness of rare chromosome disorders, their high incidence and their significance, both in the UK and overseas, and works closely with professional contacts.

Activities

Unique's core charitable activities are categorised under two primary headings:

1. Family Support Services
2. Awareness-raising.

1. Family Support Services

Unique acts as an international support group and aims to provide the following core services on an ongoing basis:

- A high-quality magazine *Unique* produced three times each year and distributed to members.
- A comprehensive website at www.rarechromo.org, which attracts the worldwide rare chromosome disorder community to Unique.
- A 24-hour helpline service to support families needing information and to relieve parents and carers in times of distress and isolation.

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2007

- A family conference held in the UK to bring together families and professionals and share knowledge of advances in diagnosis as well as information helpful in the daily lives of those affected by a rare chromosome disorder.

To provide the core support group services, Unique has developed the following resources:

- A confidential offline database updated at least once a year, which keeps individual records showing the lifetime effects and consequences of specific rare chromosome disorders on each affected member of Unique. This constitutes a unique resource that is not available anywhere else in the world. The Unique database manager uses the data to respond to requests for information from clinical geneticists, researchers and other professionals as well as from families and people with rare chromosome disorders.
- The Unique information project, which builds on our range of published material to support more families affected by rare chromosome disorders.
- Indirect family support delivered via professionals which builds on our existing relationships with professional bodies and individuals working with families affected by rare chromosome disorders, including contributions to medical research into the effects and health issues relating to rare chromosome disorders.

2. Awareness-raising

Unique aims to educate the general public about rare chromosome disorders through talks and presentations and using national and local media when appropriate. Unique also seeks out opportunities to educate policy-makers about rare chromosome disorders and their effects on family life.

Achievements and Performance

1. Family Support Services

Membership of Unique continues to grow at a steady rate, illustrated by the following figures:

| | 31 Mar 04 | 31 Mar 05 | 31 Mar 06 | 31 Mar 07 |
|------------------------------|------------------|------------------|------------------|------------------|
| Family Members (cumulative) | 4,000 | 4,500 | 4,920 | 5,350 |
| New Families | 488 | 412 | 400 | 430 |
| Total Countries (cumulative) | 64 | 65 | 68 | 69 |

Whilst we have 5,350 member families, this actually represents over 6,000 affected individuals with a rare chromosome abnormality.

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2007

Magazine

We published our highly acclaimed magazine three times during the year, in which families and professionals shared their knowledge and experiences. To many families, the magazine is seen as the 'face' of Unique. The full-colour magazine is professionally produced to a high standard, with each issue costing around £10,000 to produce and distribute to members. Features included:

Spring 2006

- a day in the life of a Clinical Geneticist
- an article on Self-Injurious behaviour
- a guide to the new DfES Directive on LEA Statements

Summer 2006:

- a day in the life of a Genetic Counsellor
- an article on communication entitled "I CAN's Talking Point website"
- an article on transition entitled "A time for change"
- general information on how to access holiday cash and a charity that helps families with disabled children manage debt.

Autumn 2006:

- a day in the life of a Clinical Cytogeneticist,
- an article on equipment entitled Disabled Children Deprived and Injured
- under our money matters section an article covering The Independent Living Fund
- general information under special needs on Adaptations to your house, Changing lives campaign, Early Support Information for Parents and What is the government doing to help families and carers

Website: www.rarechromo.org

| | 31 Mar 04 | 31 Mar 05 | 31 Mar 06 | 31 Mar 07 |
|--|------------------|------------------|------------------|------------------|
| Website 'hits' (cumulative) | 87,798 | 119,569 | 170,193 | 304,738 |
| Messages posted on members' forum (cumulative) | 2,000 | 2,352 | 2,876 | 3,239 |

Members can go to "collect" an electronic version of the magazine from the new magazine archive held in the password-protected part of the website. So far over 876 member families have chosen the electronic delivery route, saving the group a considerable sum in postage and printing costs.

Over 60 booklets and flyers about rare chromosome disorders can be accessed through and downloaded from the password-protected members' area with many more to come.

Helpline

| | 31 Mar 04 | 31 Mar 05 | 31 Mar 06 | 31 Mar 07 |
|----------------------------------|------------------|------------------|------------------|------------------|
| Telephone enquiries (cumulative) | 4,500 | 5,200 | 6,000 | 6,700 |
| Email enquiries (cumulative) | 32,146 | 49,560 | 73,200 | 95,800 |

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2007

The CEO continues to support the 24-hour helpline and acts as the initial point of contact for all new families.

Conference

The last Unique conference took place in October 2005. Our 12th conference was planned for October 2007 but no suitable accommodation was available in our chosen geographic area of the Midlands at that time. Consequently the next Unique conference is planned for October 2008 near Daventry.

Maintaining the Unique Database

Unique maintains a comprehensive offline database detailing lifetime effects of specific chromosome disorders on individual members, providing an invaluable source of information for new and existing members and professionals. From the database, staff are able to provide inquiring professionals with anonymised information about the effects of a specific rare chromosome disorder. This is particularly helpful when there is no Unique information leaflet on a specific condition. Feedback from professionals, especially geneticists and paediatricians, has demonstrated that this service has proved invaluable to them in counselling and managing affected families.

An anonymised shortened version of the full Unique database is held on the public website, allowing professionals and families themselves to search through the specific rare chromosome disorders (with karyotype where available) of every affected member in the group.

Information Project

For four years the Information Officer has researched and produced family-friendly, medically verified leaflets and flyers on more than 60 specific chromosome disorders. Most of these are now available to our members via a password-protected area on our website.

In addition a range of articles on a wide range of topics affecting families' daily lives (e.g. carers' and disability legislation, educational issues and communication for disabled children) is available from the public pages of our website.

Other Unique publications include:

- Little Yellow Book - volume 1, a guide to rare chromosome disorders for families and non-genetics professionals. The book translates technical terminology and complicated scientific concepts into accessible language.
- Unique Tales, a cartoon strip aimed at 7 to 10 year olds to help explain rare chromosome disorders to siblings of affected children.
- Volume 2 of the Little Yellow Book should be available to download via the website in 2007.

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2007

Indirect Family Support delivered via Professionals

Unique informs professionals, including geneticists, GPs, paediatricians, special needs teachers and social workers, health visitors, community paediatric nurses and midwives as well as members of other support groups, on how the group offers information and support when a family is newly diagnosed. This has been achieved in a number of ways:

- Unique has given numerous presentations to professionals over the past twelve months and has been invited to contribute as expert patient representative to a number of professional committees and working groups.
- Unique has been pivotal in helping to develop a virtual network (Eurochromnet) of RCD support groups across Europe aimed at raising awareness and spreading high quality information and best practice across the Continent, while breaking down language and cultural barriers. Unique is an active member of the European Rare Diseases Organisation and provides advice to the Human Genetics Commission.
- Unique has presented at the British Society of Human Genetics Annual Conference and, for the last four years, was invited to participate with an awareness-raising stand that attracted widespread attention. The majority of delegates were clinical geneticists, genetic counsellors, genetic nurses, cytogeneticists and molecular geneticists from across the UK, as well as from abroad.

Unique is a partner in two pan-European projects involving a wide range of genetics professionals and researchers:

- A network of excellence, Eurogentest (Genetic Testing in Europe – Integrated network for test development harmonisation, validation and standardisation of services). Participation in this network has led to some excellent contacts in the genetics world in Europe and beyond and has prompted many families to come to Unique for help.
- A second EC project, SAFE (Special Non-Invasive Advances in Foetal and Neonatal Evaluation), a network of excellence involving 50 research groups from across Europe investigating non-invasive methods of testing and diagnosis for genetic abnormalities both *in utero* and in the neonatal stage.

Trustees' Summary

The trustees continue to be delighted by the excellent outcomes of the charity's core Family Support Services.

The trustees recognise that the huge frontline response to families, much of it bespoke, is generated by a tiny number of highly dedicated staff. Thanks are due to all employees who work hard to support families by providing prompt information and creating opportunities for social contact to relieve often profound feelings of isolation. Special mention must be made of the long hours put in by the CEO herself to provide an instant response of the highest quality to every inquiry. Additional resources have been allocated to increase support for staff performing this invaluable service.

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2007

The trustees are very grateful to the Information Officer and CEO for their commitment to producing the range of information on specific rare chromosome disorders that we have to date. The information project is the jewel in our crown as it provides a truly unique service to these families and the professionals supporting them.

Although we held no Conference this year, our Family Support Officer did not cease her ongoing research into suitable venues for the next one. 'The Conference' is on the agenda of every committee meeting and we acknowledge how much effort goes into its preparation behind the scenes. Our Family Support Officer provides an indispensable quality backup to the CEO and is herself held in high esteem by member families. The trustees and staff value highly her input and personal qualities and, alongside our Life President and the CEO, the Family Support Officer continues to bring continuity to the team.

We are grateful, too, to the Assistant Information Officer for the quality of her response to families' need for more general information on issues that affect their lives with children who may develop multiple and complex needs including highly challenging behaviour that is often misunderstood by the wider community. The trustees were sorry not to be able to continue to provide this service when the dedicated grant ran out in August 2006.

The trustees are pleased that relationships with key professionals keep the group expanding and enhance the quality of its work and reputation. We are proud of the reputation that Unique has developed among genetics and other professionals, due entirely to the knowledge and skills of our key staff. Unique could not operate without support from the medical and other professionals who work with affected families and will continue to invest resources in this important area.

2. Awareness Raising

Unique runs a UK and global network of local contacts who distribute the group's awareness-raising posters and information leaflets to local hospitals, social work departments, doctors' surgeries and special schools. New members receive an introductory pack with awareness-raising literature to distribute in their local area.

Unique is promoted on innumerable public information databases and has established good working relationships with a variety of organisations including Contact a Family (CaF), the Genetic Interest Group (GIG) and DECIPHER a database of submicroscopic chromosomal imbalance. All these organisations refer families and individuals affected by rare chromosome disorders to Unique.

Unique raises awareness of rare chromosome disorders and of the support group through local and national media and actively encourages families to mention Unique in any press articles or radio or television interviews in which they may get involved.

The Royal Bank of Scotland Foundation's Christmas 2006 donation to the most-voted-for children's charity, promoted through the Daily Mail newspaper, earned Unique national public recognition in a sympathetic manner. When it beat many larger, higher-profile charities to first place, Unique was noticed by the wider not-for-profit community. Receiving the award, trustees and staff spent time with the Rt Hon Beverley Hughes MP, Minister for Children, Young People and Families, talking about the challenges faced by Unique's family members.

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2007

Trustees' Summary

The trustees are pleased with the positive results from contacts made with genetics and other professionals and other support groups as well as with the wider world. Tailoring Unique's resources to its income will continue, however, to restrict expansion of Unique's existing capacity and until income increases, publicity campaigns must remain reactive rather than proactive. It is important that Unique's ability to offer a first-class service to new and existing family members remains unimpaired. Without more resources, Unique would not be able to respond to the results of a high-profile advertising campaign, however desirable this might be from the perspective of all families with a chromosome disorder and of those who support them.

Financial Review

Our primary source of unrestricted income is members, their friends and family through donations and fundraising. We are extremely grateful to all those who made contributions – there was a significant increase in income from our members this year. We are now generating additional revenue directly from the sale of Christmas cards and other merchandise as well as a subscription for professionals to access our information booklets via an annual licence.

In 2006, for the first time we submitted our online accounts for consideration for the CAF Charities Online Accounts Award. We were delighted to win third place in our annual income category (£100,000 to £249,999). The trustees wish to thank our Finance & Fundraising EO, who prepared the accounts and IT specialist Trevor Searle, for converting them to an online format.

We feel it appropriate to express our special thanks to the Finance & Fundraising EO for the timely, comprehensive figures with which she presents us at the end of each month. For trustees to discharge their responsibilities in diligent fashion and to feel comfortable in their role, such information is absolutely crucial. We are enormously indebted to Julie for the competent manner in which she approaches all tasks, allowing us the reassurance of knowing that the financial functions of the group are in safe hands. Her contributions to the magazine are always of great interest and her contacts with members wishing to donate to or fundraise for the group are clearly effective. This member of staff, again, donates much extra time to her role, facilitating the work of her colleagues and the charity's future success.

Grants

Unique was grateful to receive a number of grants this year. Donors included:

- The Health Foundation ~ a contribution to the running costs of the information project
- Children in Need ~ provided restricted funding for the Assistant Information Officer's post
- Lloyds TSB Foundation England & Wales ~ provides restricted funding towards costs of maintaining the Unique database

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2007

- Royal Bank of Scotland Charitable Trust ~ a tremendous boost to income came from the RBS 2006 Christmas Giveaway competition. RBS staff and Daily Mail readers voted for their favourite children's charities and the top ten each received £10,000. A second public voting round saw Unique receive the most votes out of all ten charities, most of them household names, and the top prize of £100,000. This award has facilitated an expansion in 2007 in Unique's capacity to welcome new families and in the information project.

Investments

In September 2005 two Tracey Emin prints, "Little Family", were donated to Unique, valued independently at £700 each. In October 2006, one print was auctioned as part of the CAF eBay celebrity auction for National Giving Week and raised £2,250. A Red Arrows flying suit donated by a member achieved a further £1,000.

Expenditure

Costs associated with the magazine are proportionate to the increase in membership, the increase in content of the magazine and related postage costs. Website and helpline running costs continue to be managed efficiently and are subsidised significantly by voluntary support. Resources used to support families via professionals are within budget. With the additional income, including professionals' subscriptions received this year, we can now build on our services and provide more information and support to professionals serving the rare chromosome disorder community.

Gifts in Kind

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

- Trevor Searle, for his expertise, time and inexhaustible patience spent on updating the Unique website and online capabilities. Without this free in-house resource, Unique would not have been able to develop and maintain its website and database.
- Professor Maj Hulten, who has been a major influence and support in the work with EC partners as well as spending countless hours checking and verifying Unique's publications on specific disorders. Over the years, Maj has provided the professional geneticist's view to the management committee.
- Carey Hunt, committee member, who provides her professional creative skills to design the excellent Unique publications.
- Lydia Dickie who, as a committee member, continues to provide well-informed contributions on areas of interest to Unique families.
- Sarah Trevitt for her work in organising our ever-increasing number of marathon runners entering an every-increasing number of races .
- the busy volunteers who despatch the magazine three times a year, a Herculean task.

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2007

We should like, as well, to recognise the generous contribution to the group of our fellow trustee, company secretary Eleanor Fiske, who gives freely of her time, professional experience, expertise and energy to meet the legal and secretarial needs of the group. Eleanor's guidance has been of inestimable value since she joined the charity's management committee and she plays a leading role on our ethics panel.

Reserves Policy

The trustees aim to hold between 3 and 6 months of expenditure in reserves, which equates to £45,000 to £95,000 in general funds. At this level, the trustees feel that they would be able to honour current commitments in the event of a significant drop in income. At 31 March 2007 unrestricted funds of £205,433 were held. This unusually high figure results from the recent receipt of £100,000 from the RBS Foundation. With the planned increase in expenditure on core services, the financial situation at year-end is felt to be entirely appropriate.

Plans for the Future

The trustees' immediate plans for the future include:

- Continuing to provide existing support for families affected by rare chromosome disorders in order to relieve feelings of isolation and despair.
- Expanding services to meet the growing demand from both existing members and new members each year.
- Continuing to develop the information project and to increase income to permit an expansion of this service while reducing the current unreasonable burden on existing staff who work well beyond their paid hours to meet needs.
- Securing ongoing funding from a number of different income streams so that the future of the charity's core activities: helpline, magazine, database and information project: is assured.
- Implementing the group's four-year operating plan to achieve these goals.

Key to the successful delivery and expansion of Unique's core services is the number and quality of its staff. With the RBS win, funds became available to expand the capacity of both information project and the CEO's frontline work with families and professionals. Grant applications have been submitted for specialist support workers so that we can embark on an outreach project to find the 'hidden' families perhaps most in need of our services, simultaneously raising public and professional awareness throughout the UK. We wish to broaden what we can offer to our more mature young people. However our fundamental position is that there will be no expansion unless we can be sure of maintaining the high quality of personalised response to each and every member family. This is what Unique is known for and why the group is valued so highly.

As trustees, it is our aim during the coming year to ensure the development of a sound infrastructure to underpin growth and assure continued quality. With one in 200 of the general population likely to be affected by some sort of rare chromosome disorder during their life, pressure on Unique's services will be unremitting. It is our role to ensure that the group can continue to welcome everybody faced with such a devastating diagnosis and provide 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 2007

Over the year we have appreciated the positive partnership with Pilotlight, a non-profit organisation marrying business mentors to charities wishing to develop their operations. As staff build Unique's administration functions, they will benefit from the experience and expertise on offer from these business lions.

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 total number of such guarantees at 31 March 2007 was 8. The trustees are members of the charity but this entitles them only to voting rights. The trustees have no beneficial interest in the charity.

Auditors

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

Approved by the trustees on 7 July 2007 and signed on their behalf by

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 2007 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 2007 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.

10 July 2007

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 2007

| | Note | Restricted £ | Unrestricted £ | 2007 Total £ | 2006 Total £ |
|--|------|-----------------|-------------------|--------------------|--------------------|
| Incoming Resources | | | | | |
| <i>Incoming Resources from Generated Funds:</i> | | | | | |
| | 2 | | | | |
| Voluntary Income | | - | 186,107 | 186,107 | - |
| Activities For Generating Funds | | - | 58,007 | 58,007 | - |
| Investment Income | | - | 5,118 | 5,118 | - |
| <i>Incoming Resources from Charitable Activities:</i> | | | | | |
| | 3 | | | | |
| Family Support Services | | 27,821 | - | 27,821 | - |
| Awareness Raising | | - | - | - | - |
| Total Incoming Resources | | 27,821 | 249,232 | 277,053 | - |
| Resources Expended | | | | | |
| <i>Costs of Generating Funds:</i> | | | | | |
| Fundraising & Merchandise Costs | | - | 9,665 | 9,665 | - |
| <i>Charitable Activities:</i> | | | | | |
| Family Support Services | | 24,177 | 96,393 | 120,570 | - |
| Awareness Raising | | - | 12,312 | 12,312 | - |
| Governance Costs | | - | 9,987 | 9,987 | - |
| Total Resources Expended | 4 | 24,177 | 128,357 | 152,534 | - |
| Net Incoming Resources Before Gains & Transfers | | 3,644 | 120,875 | 124,519 | - |
| Gains on Investment Assets | 5 | - | 1,550 | 1,550 | - |
| Net Movement in Funds | | 3,644 | 122,425 | 126,069 | - |
| Transfers of Funds from Charitable Trust | 15 | 3,295 | 83,008 | 86,303 | - |
| Reconciliation of Funds | | | | | |
| Total Funds Brought Forward | | - | - | - | - |
| Total Funds Carried Forward | | 6,939 | 205,433 | 212,372 | - |

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 2007

| | Note | £ | 2007 £ | 2006 £ |
|---|------|----------------|-----------------------|-----------|
| Fixed Assets | | | | |
| Tangible Fixed Assets | 9 | | 1,194 | - |
| Investments | 10 | | <u>700</u> | - |
| | | | 1,894 | - |
| Current Assets | | | | |
| Stock | 11 | 1,203 | | |
| Debtors | 12 | 12,731 | | - |
| Cash at Bank and in Hand | | <u>201,054</u> | | - |
| | | 214,988 | | - |
| Creditors: Amounts Due Within 1 Year | 13 | <u>4,510</u> | | - |
| Net Current Assets | | | <u>210,478</u> | - |
| Net Assets | 14 | | <u><u>212,372</u></u> | - |
| Funds | | | | |
| Restricted Funds | 15 | | 6,939 | - |
| Unrestricted Funds: | | | | |
| General funds | | | <u>205,433</u> | - |
| Total Funds | | | <u><u>212,372</u></u> | - |

Approved by the trustees on 7 July 2007 and signed on their behalf by

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 2007

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 whichever 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 |
|--------------------|---------|

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 fund.
- 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.

Rare Chromosome Disorder Support Group

Notes to The Financial Statements

For The Year Ended 31 March 2007

2. Incoming Resources From Generated Funds

| | Restricted £ | Unrestricted £ | 2007 Total £ | 2006 Total £ |
|--|-----------------|-------------------|--------------------|--------------------|
| <i>Voluntary Income:</i> | | | | |
| Royal Bank of Scotland Charitable Trust | - | 100,000 | 100,000 | - |
| Health Foundation | - | 15,925 | 15,925 | - |
| Bernard Sunley Foundation | - | 2,000 | 2,000 | - |
| Share Gift | - | 1,000 | 1,000 | - |
| Grants < £1,000 | - | 2,345 | 2,345 | - |
| General Donations | - | 19,635 | 19,635 | - |
| Donated Goods / Services * | - | 19,515 | 19,515 | - |
| Gift Aid | - | 8,230 | 8,230 | - |
| Corporate Donations | - | 5,748 | 5,748 | - |
| Covenants | - | 4,497 | 4,497 | - |
| Overseas Donations | - | 3,105 | 3,105 | - |
| Give As You Earn | - | 2,180 | 2,180 | - |
| Little Yellow Book | - | 1,260 | 1,260 | - |
| Pyramids | - | 668 | 668 | - |
| <i>Total Voluntary Income</i> | - | 186,107 | 186,107 | - |
| <i>Activities For Generating Funds:</i> | | | | |
| Fundraising Activities | - | 54,653 | 54,653 | - |
| Christmas Card & Merchandise Sales | - | 3,354 | 3,354 | - |
| <i>Total Activities For Generating Funds</i> | - | 58,007 | 58,007 | - |

* Donated services consist of the following:

| | |
|--|---------------|
| Website & database design, development & maintenance | 12,015 |
| Professional verification of information in the charity's publications | 5,700 |
| Installation of IT equipment | 1,800 |
| Total Donated Services | 19,515 |

3. Incoming Resources From Charitable Activities

| | Restricted £ | Unrestricted £ | 2007 Total £ | 2006 Total £ |
|---|-----------------|-------------------|--------------------|--------------------|
| <i>Family Support Services:</i> | | | | |
| Charles Hayward Foundation | 10,000 | - | 10,000 | - |
| Lloyds TSB Foundation | 10,000 | - | 10,000 | - |
| K U Leuven R&D - Eurogentest | 2,702 | - | 2,702 | - |
| BBC Children in Need | 2,726 | - | 2,726 | - |
| EU Grant - SAFE Project | 2,393 | - | 2,393 | - |
| <i>Total Income for Family Support Services</i> | 27,821 | - | 27,821 | - |

The Rare Chromosome Disorder Support Group

Notes to the Financial Statements

For The Year Ended 31 March 2007

4. Total Resources Expended

| | -----Family Support Services----- | | | | | | | | |
|-----------------------------------|---|--|---------------|------------------------|--|---------------------------|--------------------------|-----------------------------|-----------------|
| | Fundraising & Merchandise Costs £ | Magazine, Website, Helpline & Conference £ | Database £ | Information Project | Indirect Family Support by Professionals | Awareness Raising £ | Governance Costs £ | 2007 Total £ | 2006 Total £ |
| Staff Costs (Note 7) | 4,367 | 23,879 | 7,851 | 23,384 | 6,677 | 7,378 | 5,264 | 78,800 | - |
| Postage | 557 | 13,935 | 2,787 | 372 | 372 | 557 | - | 18,580 | - |
| Printing & Design | 953 | 11,915 | 1,271 | 318 | 636 | 794 | - | 15,887 | - |
| Stationery | 405 | 405 | 405 | 405 | 406 | 406 | - | 2,432 | - |
| Subscriptions, Licences & Charges | 432 | 433 | 433 | 433 | 433 | 433 | - | 2,597 | - |
| Travel & Subsistence | 65 | 782 | 65 | 109 | 434 | 716 | - | 2,171 | - |
| Meetings | - | - | - | - | - | - | 2,138 | 2,138 | - |
| Equipment & Software | 520 | 519 | 519 | 519 | 519 | 519 | - | 3,115 | - |
| Merchandise | 856 | - | - | - | - | - | - | 856 | - |
| Telephone & Internet | 300 | 300 | 300 | 300 | 300 | 299 | - | 1,799 | - |
| Premises Overheads | 76 | 77 | 77 | 77 | 77 | 76 | - | 460 | - |
| Website & Database Development | 601 | 8,411 | 2,403 | - | - | 600 | - | 12,015 | - |
| Insurance | 430 | 429 | 429 | 429 | 429 | 430 | - | 2,576 | - |
| Audit & Accountancy | - | - | - | - | - | - | 2,585 | 2,585 | - |
| Consultancy | - | - | - | 5,900 | - | - | - | 5,900 | - |
| Depreciation | 103 | 104 | 104 | 104 | 104 | 104 | - | 623 | - |
| Total Resources Expended | 9,665 | 61,189 | 16,644 | 32,350 | 10,387 | 12,312 | 9,987 | 152,534 | - |

Rare Chromosome Disorder Support Group

Notes to the Financial Statements

For The Year Ended 31 March 2007

5. Gains on Investments

The gain was generated by the sale of one of the Tracey Emin prints which was previously held under investments. The gain was calculated as follows:

| | |
|--|--------------|
| Sale Proceeds | 2,250 |
| Less: Market Value of Investment at 1 April 2006 | (700) |
| | <hr/> |
| Gain on Investment | 1,550 |
| | <hr/> <hr/> |

6. Net Movement in Funds

This is stated after charging:

| | 2007 | 2006 |
|-------------------------------|--------------|-------------|
| | £ | £ |
| Depreciation | 623 | - |
| Trustees' indemnity insurance | 1,575 | - |
| Trustees' reimbursed expenses | Nil | - |
| Auditors' remuneration: | | |
| ▪ Statutory Audit | 2,350 | - |
| ▪ Under-Accrual in Prior Year | 235 | - |
| | <hr/> <hr/> | <hr/> <hr/> |

7. Staff Costs and Numbers

Staff costs were as follows:

| | 2007 | 2006 |
|-----------------------|---------------|-------------|
| | £ | £ |
| Salaries and Wages | 72,153 | - |
| Social Security Costs | 6,386 | - |
| Casual Staff | 261 | - |
| | <hr/> <hr/> | <hr/> <hr/> |
| | 78,800 | - |

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

| | 2007 | 2006 |
|--|-------------|-------------|
| | No. | No. |
| Average number of employees (full-time equivalent) | 3.24 | - |
| | <hr/> <hr/> | <hr/> <hr/> |

8. Taxation

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

Rare Chromosome Disorder Support Group

Notes to the Financial Statements

For The Year Ended 31 March 2007

9. Tangible Fixed Assets

| | Total £ |
|--|---------------------|
| Cost | |
| At 1 April 2006 | - |
| Transfer from Charitable Trust | 1,351 |
| Additions in year | <u>1,142</u> |
| At 31 March 2007 | <u>2,493</u> |
| Depreciation | |
| At 1 April 2006 | - |
| Transfer from Charitable Trust | 676 |
| Charge for the year | <u>623</u> |
| At 31 March 2007 | <u>1,299</u> |
| Net Book Value At 31 March 2007 | <u><u>1,194</u></u> |
| At 31 March 2006 | <u><u>-</u></u> |

10. Investments

| | 2007 £ | 2006 £ |
|---------|------------|-----------|
| Artwork | <u>700</u> | <u>-</u> |

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

| | 2007 £ | 2006 £ |
|-------------|--------------|-----------|
| Merchandise | <u>1,203</u> | <u>-</u> |

Rare Chromosome Disorder Support Group

Notes to the Financial Statements

For The Year Ended 31 March 2007

12. Debtors

| | 2007 £ | 2006 £ |
|---------------|----------------------|-----------------|
| Prepayments | 6,022 | - |
| Other Debtors | <u>6,709</u> | <u>-</u> |
| | <u><u>12,731</u></u> | <u><u>-</u></u> |

13. Creditors : Amounts Due Within 1 Year

| | 2007 £ | 2006 £ |
|----------------------------------|---------------------|-----------------|
| Accruals | 2,627 | - |
| Other Taxation & Social Security | <u>1,883</u> | <u>-</u> |
| | <u><u>4,510</u></u> | <u><u>-</u></u> |

14. Analysis of Net Assets Between Funds

| | Restricted Funds £ | Unrestricted Funds £ | Total Funds £ |
|------------------------------------|--------------------------|----------------------------|-----------------------|
| Tangible Fixed Assets | - | 1,194 | 1,194 |
| Investments | - | 700 | 700 |
| Current Assets | 6,939 | 208,049 | 214,988 |
| Current Liabilities | <u>-</u> | <u>(4,510)</u> | <u>(4,510)</u> |
| Net Assets at 31 March 2007 | <u><u>6,939</u></u> | <u><u>205,433</u></u> | <u><u>212,372</u></u> |

Rare Chromosome Disorder Support Group

Notes to the Financial Statements

For The Year Ended 31 March 2007

15. Movements in Funds

| | At 1 April 2006 £ | Transfer of Funds From Charitable Trust £ | Incoming Resources £ | Outgoing Resources £ | Gains on Investments £ | At 31 March 2007 £ |
|-------------------------------------|-------------------------|---|----------------------------|----------------------------|------------------------------|-----------------------------|
| Restricted Funds | | | | | | |
| Charles Hayward Foundation | - | - | 10,000 | (10,000) | - | - |
| BBC Children in Need | - | 871 | 2,726 | (3,597) | - | - |
| Lloyds-TSB Foundation | - | - | 10,000 | (10,000) | - | - |
| SAFE Fund | - | 268 | 2,702 | (108) | - | 2,862 |
| Eurogentest Fund | - | 2,156 | 2,393 | (472) | - | 4,077 |
| Total Restricted Funds | - | 3,295 | 27,821 | (24,177) | - | 6,939 |
| Unrestricted Funds | | | | | | |
| General Funds | - | 83,008 | 249,232 | (128,357) | 1,550 | 205,433 |
| Total Unrestricted Funds | - | 83,008 | 249,232 | (128,357) | 1,550 | 205,433 |
| Total Funds | - | 86,303 | 277,053 | (152,534) | 1,550 | 212,372 |

Transfer of Funds From Charitable Trust

The assets, liabilities and activities of the charitable trust (no. 1024624) were transferred to a newly incorporated charitable company on 1 April 2006. All restricted funds transferred to the new charitable company will be spent in line with the original restrictions imposed by the donor.

Purposes of Restricted Funds

| | |
|----------------------------|---|
| Charles Hayward Foundation | To fund part of the Information Officer's salary |
| BBC Children in Need | To fund the Assistant Information Officer's salary |
| Lloyds-TSB Foundation | To fund database development and maintenance |
| SAFE Fund | To fund all costs associated with the SAFE project |
| Eurogentest Fund | To fund all costs associated with the Eurogentest project |

Company no. 5460413
Charity no. 1110661

**Rare Chromosome Disorder Support
Group
Report and Financial Statements
31 March 2007**

