Company no. 5460413
Charity no. 1110661

Rare Chromosome Disorder Support Group

Report and Financial Statements

31 March 2010

Rare Chromosome Disorder Support Group

Contents

For The Year Ended 31 March 2010

Rare Chromosome Disorder Support Group

Reference and Administrative Details

For The Year Ended 31 March 2010

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:	
	Gillian Manvell	Chairman
	Edna Knight	Founder, Life President
	Eleanor Fiske	Company Secretary - (resigned January 2010)
	Sophie Sainty	(appointed December 2009)
	Michael Toothill	(appointed January 2010)
	David Williams	
Principal Staff	Beverly Searle	Chief Executive Officer
	Craig Mitchell	Operations Manager (appointed as Company Secretary in January 2010)
	Marion Mitchell	Family Support Officer
	Prisca Middlemiss	Senior Information Officer
	Sarah Wynn	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 & Statutory Auditors Unit 5.11 Paintworks Bath Road Bristol BS4 3EH	

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2010

The trustees present their report and the audited financial statements for the year ended 31 March 2010.

Chairman's Statement

The year ended 31 March 2010 has been another period of outstanding success. Thanks to dedicated staff and generous donors, we met the challenge of unstoppable membership growth associated with a huge increase in rare chromosome disorder (RCD) diagnoses. Unique will continue to help thousands of families and medical professionals every year but needs to step up its fundraising to meet the needs of a rapidly-increasing membership.

Aims of the charity

Edna Knight MBE, mother of children affected by a RCD, founded Unique in 1984 as a family support group. Now, twenty-six years later, Unique remains a charity specialising in the support of families affected by rare chromosome disorders through the provision of high-quality, relevant information and personal contacts.

Unique aims to reduce the isolation caused by a RCD diagnosis by providing support, sharing information between affected families and improving public awareness of the effects of RCDs.

"When I received my older daughter's diagnosis back in 2009, I definitely wanted to know that I was not alone. That there were other parents out there or even grown adults out there that were dealing with the same thing. I wanted hope for my daughter, I felt like the world around my child got crushed. But thanks to Unique I had a clearer understanding of what she was going through and why different things happened in her world."
[Quote from a parent member]

- We deliver support to families via our 24-hour helpline, website with discussion forum and social networking sites.
- Our unique information source is an in-house, comprehensive, lifetime database on RCDs, constantly updated.
- We produce downloadable chromosome disorder guides.
- We give information to professionals such as doctors, geneticists, social workers and special educationists, to help them support families affected by RCDs.
- We raise public awareness of the impact of a RCD on family life.
- We hold specialist Family Conference Weekends and Study Days and provide speakers for medical and other organisations.
- Our ethics committee considers research projects that could benefit our members.

Our performance in 2009/10

Finances

Membership of Unique continues to be free to families so that we reach as many people as possible and, crucially, can collect data on as many individuals affected by RCDs as possible. Reaching more and more members does present, however, a serious financial challenge to Unique.

In 2005 we were serving 4,500 member families with an income of £216,000.

Five years later, we are looking after 60% more families (7,200) on an income of £269,000.

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2010

Fundraising

During the year, Unique's total income from grants, donations and members' fundraising efforts exceeded our conservative forecasts. This was due in part to the hire of our first professional fundraiser but also, to our members raising more than ever before. Coupled with a number of new grants, this ensured that services were maintained, even improved upon, throughout the year.

With a slow recovery predicted for the UK economy, austerity measures affecting the general population and continuing low interest rates, we do not foresee any substantial rise in income from current sources in the new financial year. The steady increase in members' fundraising activities cannot possibly keep pace with the expected rise in families in need. To be able to meet families' needs, we require a substantial increase in income from charitable trusts and major donors. After the past year's success, in the new financial year we have decided to recruit an experienced fundraising professional on a part-time, fixed-term basis, to help us pursue this objective.

To ensure that we never have to turn away new members needing help, we aspire to recruit additional staff to continue the existing programme of family support and database development work. Longer term, funds permitting, we have plans to improve and increase our services.

Our people

Unique was founded and is led principally by families of children and young people with RCDs for the benefit of everyone with RCDs. We thank all our members for their support and belief in Unique.

The Trustees are grateful to our CEO Beverly Searle, her management team and staff for their diligent delivery of services this year and for their hard work and dedication in promoting the charity. Unique's team achieves the near impossible: the delivery of an ever-increasing volume of services without diminishing quality. The high profile Unique is gaining, for example, in being selected as a 2009 Jeans4Genes guest charity hard on the heels of a GSK IMPACT Award for excellence in community healthcare in early 2009, speaks for itself.

The entire leadership team must express its thanks, too, for the support of those many professionals who donate their experience, expertise, judgement and time to Unique in the interests of the charity and of its thousands of members around the world.

I hope you will find this report an illuminating read and that it will help you understand that we have much more work to do. The challenge ahead is how to develop and fund that work.

Gill Manvell, Chairman of Trustees • July 2010

What are rare chromosome disorders?

Rare chromosome disorders are genetic disorders, present in a person's makeup at or around birth, which may lead to medical, intellectual, social, behavioural, reproductive or other problems. RCDs are caused by extra, missing or re-arranged parts on an individual's chromosomes, either inherited from parents with an RCD or occurring spontaneously at conception. RCDs do not include the more common and better known chromosome conditions such as Down's Syndrome which are well described in medical literature and which have their own dedicated support organisations.

How common are RCDs?

Individually, RCDs are indeed very rare but collectively, they are common.
At least 1 in every 200 babies is born with a RCD.
At least 1 in every 1,000 babies has symptoms from birth or early childhood; the rest may find they are affected when they try to have babies of their own.

These statistics are set to rise very rapidly as many more babies (and previously undiagnosed adults and children) can be diagnosed now with RCDs detected through Array CGH analysis, a recently developed, more detailed form of genetic testing.

Some RCDs are so rare that they are actually unique. Usually it is immediately following diagnosis that affected families and individuals have the greatest need for emotional and practical support and, above all, for information.

How much do doctors know?

Even among the more common "rare" disorders, it is likely that professionals in the local community - GP, Social Worker or even hospital specialists - will have never before come across anyone with the same disorder. The usual sources of support are not available to affected families, yet the effects of these disorders can be devastating. The vast majority of families have a desperate feeling of isolation. Under the umbrella of Unique membership, families benefit from mutual support and linking with other members who will share experiences, even when their actual chromosome disorders are quite different.

How do you test for RCDs?

Genetic testing examines a person's DNA. DNA is present in almost every cell in our bodies and is bundled into packages called chromosomes. Most people have 46 chromosomes in every cell of their bodies. These chromosomes exist in two sets: we inherit one set of 23 chromosomes from our mother and one set of 23 chromosomes from our father. In this way, DNA is passed from parent to child and contributes to development and health. The genetic testing of patient's blood (often called karyotyping), available over the last thirty years, detected comparatively large gains or losses of chromosomes or segments of chromosomes.

Using the latest technology, called "Array CGH" (microarray-based comparative genomic hybridization), it is now possible for smaller and more complex chromosome defects to be identified.

The future: Beating the isolation associated with RCDs

In the coming year Unique will continue to refer to its five-year operating plan for 2006-11 which clarified the charity's vision and aims, set itsstrategic direction and defined the operational parameters. The trustees confirm that they have referred to the Charity Commission's general guidance on public benefit when reviewing Unique's aims and objectives,, planning future activities and setting policy for the year.

The strategy for 2006 - 11 is to:

- **Expand membership**
  double membership, retaining high-quality personalised services.

- **Publish more**
  increase annual output of RCD Guides by 60%.

- **Increase research participation**
  from 6 to 20 appropriate projects per annum.

- **Increase awareness**
  within all circles: medical, government, public, RCD families.

- **Increase number of volunteers**
  extend our network of worldwide local contacts from 135 to 160 and increase the number and range of other *ad hoc* volunteers.

How will we achieve the strategy?
Unless there is considerable improvement in current sources of income, Unique will have to meet the needs of an increasing membership from decreasing income. This means a short-term focus on maintaining core services and fundraising followed by an increase in staff resources and forging stronger partnerships with other organisations.

Reviewing our achievements in the penultimate year of this five-year period:

- membership has increased by 60% since 2006;
- 20 new Chromosome Disorder Guides have been produced on average each year;
- Unique participated in 12 research projects in 2009-10;
- awareness of Unique has increased among all stakeholders [evidenced by the increasing number of referrals to Unique by professionals];
- we have 156 local contacts worldwide as well as many other volunteers engaged in a wide range of fundraising and social initiatives.

In March 2010, staff and trustees met to review where we are and to discuss aspirations for the next three to five years. The initial conclusions were that:

- we are a great help and support to our families. Unique's work is well respected among professionals and its reputation is outstanding;
- we should improve our engagement with the families of adults and older people affected by RCDs and work harder to reach families without internet access, those who find it difficult to find or access help and those from Black and Minority Ethnic communities;
- there is an urgent need to increase income - for which we are seeking a part-time professional fundraiser;
- once increased fundraising is in place, operational priorities will be to recruit support staff (information officer to share specialist staff overload and a database coordinator to update our database), improve our internal ICT and database management and review branding/PR to maximise awareness of Unique and its role.

In 2010-11 we shall continue to work on writing a formal operating plan for the next five years, in consultation with other stakeholders.

Family Support

Aims and objectives

Usually families contact us while reeling from the shock of a new diagnosis with an unknown and often frightening-sounding prognosis that may involve lifelong disability or medical challenges. We send them a Welcome Pack and our famous Little Yellow Book which explains RCDs and what they may mean for a child's future.

The Welcome Pack contains details of a local area contact, an experienced member of Unique who is always ready to speak to families when they want help, support or just a friendly ear. We also provide details of all local members and Unique members worldwide who share the same or similar RCD. Often our publications and contact with Unique families will provide new members with the first positive news after what may have been a gloomy, worst-case scenario from their doctors.

Unique offers families different types of support:

"Listening Ear" Support Service
The primary aim of Unique's outreach work is to beat the isolation experienced by families. Unique provides a 24 hour "Listening Ear" telephone, postal and email helpline service, which is the initial point of contact for all new families and professional inquirers. With two post-doctoral geneticists on our staff, callers are assured of reliable information.

Family Matching Service
Newly diagnosed families especially value the 'family matching' service. Unique reduces almost inevitable feelings of isolation and stress by putting families in contact with each other. Lifetime friendships arise through such contacts.

Unique Magazine
The Unique magazine, packed with families' personal stories and photographs, is sent electronically or in hard copy to members allowing families and professionals to share their knowledge and experiences with other members. The magazine also provides members with helpful information on services to which they may be entitled (medical, educational, social, financial), advice on how to obtain them as well as other practical suggestions to reduce the stresses of everyday living.

Website and Social Networking
Our website www.rarechromo.org attracts new members daily as well as worldwide interest from medical and other professionals. This up-to-date website offers a wealth of information, including ways to support the charity. Members can access a password-protected discussion forum and the magazine archive.

"It wasn't until I read other parents talking about a condition I'd never heard of on Unique's members' forum that I realised something was wrong with my son. I raised it with his doctors, who confirmed it and operated soon after."
[Quote from a grateful parent]

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2010

Performance in the past year 2009/10

Expanding membership
Unique's membership rose during the course of this year to over 7,200 member families, representing well over 8,000 affected individuals with a RCD. Our membership has increased by 66% over the past 5 years.

This dramatic increase in the number of new families joining is partly due to the work we have done to increase awareness of Unique among professionals and the general public but is also a consequence of improvements in diagnostic techniques leading to many more diagnoses of chromosomal losses and gains, including micro-deletions and micro-duplications through micro-array analysis. As a result, we expect membership of Unique to almost double within the next three years.

'Listening Ear' Support Service
The increasing uptake of this service and positive feedback from members and professionals confirms its value. During the year we received over 800 telephone enquiries and 20,000 email enquiries.

Website
Our website www.rarechromo.org continues to act as a source of new members as well as a reference for medical and other professionals. The website has received over 1 million new visits in the last 4 years. By the end of March 2010 it was regularly attracting 9,000 "absolutely unique visitors" a month. The website continues to be certified as "a reliable and credible source of health information" by the Health on the Net Foundation's Code of Conduct (HONcode) certificate.

Members' Magazine
This year we published our usual three editions of the magazine. For many, this magazine is their main contact and source of information from Unique so despite the high cost of production and postage of the magazine, the Trustees felt it was essential to protect this part of our services.

Over 3,000 member families receive it by email, saving us postage and printing costs and improving our carbon footprint. The hard copy reaches over 3,600 families, two thirds of whom are in the UK.

Social Networking
New members increasingly find Unique through searching social networking sites such as Facebook and MySpace rather than through conventional websites. Our Facebook group has developed this past year into an important tool in maintaining the support of existing members and the wider Unique community of friends and families and drawing in new families. By March 2010 we had 3,200 members of our Facebook members' page, a number which is rapidly rising. Unique keeps in contact with a further 4,000 members linked to the Rare Chromosome Disorder Support Group 'cause' page. We continue to maintain the password-protected discussion forum on our website.

Unique now has a presence on Twitter and Big Tent, means of communication which we expect to grow substantially in the coming years.

We also send out a bi-monthly e-news alert to keep friends of the group in touch with ways to support Unique and our latest news.

Plans for 2010/11

This coming year Unique plans to maintain the core provision of support for families affected by RCDs by guaranteeing the continuation of:

- Listening Ear service;
- publication of the Chromosome Disorder Guides;
- three editions a year of high-quality Magazine, packed with more family stories, information on services and on research;
- social networking response and website.

Redesign the website to make navigation easier amongst the wealth of information including members' password-protected discussion forum, the magazine archive and information on ways to support the charity.

Expand 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), broaden what we can offer to our teenage and adult members, and increase social networking support.

Launch the South West Community Group Project**,** an exciting pilot project in Bristol and the South West to bring together local members, especially isolated families or those who need face-to-face contact.

Hold further disorder-specific study weekends and possibly a Unique Family Conference if we can secure appropriate funding and staff resources.

The Information Project: database and guides

Aims and objectives

Database
First launched in 1996, Unique has developed an incomparable, comprehensive, accurate database of the disabilities, health issues, behaviour and developmental patterns experienced by those affected by thousands of the most rare chromosome disorders. Because many families have conditions which are not just 'rare' but 'ultra-rare', information is gathered not just from the UK but from around the world. Such data help families and clinicians predict and understand issues that they may have to face in future and the possible impact on the child's future development.

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

Chromosome Disorder Guides
Our database forms the basis of our ever-growing library of family-friendly, medically-verified chromosome disorder guides on specific RCDs which are available for download from the website. Started formally in 2003, the 'Information Project' now holds a store of knowledge on RCDs encompassing additional vital information provided by families as well as published research papers. We also produce guides on generic topics such as genetic testing techniques.

"We use your brochures on chromosome anomalies for our patients daily. We hope that your library will continue to expand!"
[Quote from a geneticist]

Study Days and Weekends
As part of our commitment to the support of high quality medical research, Unique holds Study Days and Weekends at which families meet clinicians and researchers to exchange information about their particular syndrome and relevant research projects.

How are we doing?
We regularly measure our performance and this year carried out a survey of our members, who told us that:

- over 90% of members who used our telephone helpline, email support service and information guides agreed or strongly agreed that they helped them better understand their child's rare chromosome disorder.

- over 90% of members agreed or strongly agreed that Unique showed them they are not alone and helped them feel less isolated by putting them in contact with other families.

- 88% were able to gain access to sources of support having seen them in the Unique magazine.

- 66% agreed or strongly agreed that information from Unique has made them aware of benefits or services to support their child's care.

- 65% agreed or strongly agreed information from Unique has helped their GP/Paediatrician understand their child's condition.

Performance in the past year 2009/10

Database
For funding reasons the annual mass mail out for updating all members' information on the database had to be postponed.

International reach
Though established in the UK, our membership spans 77 countries. This global span is essential as the rarity of some of our families' chromosome disorders means that our members may only find similarly affected people from the other side of the world. The quality of our Information Project depends on us collating data from the greatest number of families worldwide.

Study Days
The first Study Day for families affected by 1p36 chromosome disorder took place. Feedback from parents reported that the day was excellent and they learned lots of useful information. Families greatly appreciated the opportunity to meet others affected by 1p36 deletion syndrome. We received funding for a further five study weekends for families. Study Weekends for those affected by 4q Deletions, 9q34.3 Deletions, 8p23 Deletions, 2q37 Deletions and Pallister Killian Syndrome will take place in 2010-11.

Chromosome Disorder Guides
Unique's expert team of Information Officers continued this year to research and publish an ever-expanding range of family-friendly, medically-verified Chromosome Disorder Guides. As at the year-end there were more than 110 specific Chromosome Disorder Guides available to download from the website, including a guide explaining the diagnostic technique Array CGH.

We have continued to review and update current Chromosome Disorder Guides as well as publishing some guides in French, German, Italian and Spanish, providing much-needed information for non-English speaking families. Further translations will be produced in the coming year. These foreign-language publications facilitate excellent working partnerships with other European and American support charities and clinical geneticists, extending the 'pool' of families known to be affected by RCDs.

The Chromosome Disorder Guides which are downloadable from our website have attracted almost 100,000 visits alone since September 2008.

Plans for 2010/11

Database During the coming year, we aim to send each registered member family, a copy of their own database entry to amend, update and approve. This is dependent on an increase in fundraising to cover the costs of the mailing and of processing and verifying the resulting data, otherwise it may need to be scaled over a few years for cost and manpower reasons.

If funding permits, we will also be addressing the technical side of our database and how to make it more efficient to use by staff. We will also consider how the database can be developed to help better achieve all the objectives of the Charity from information and support to networking between members and fundraising.

UK genetics testing survey - We are surveying all 26 UK regional genetics centres to gain a better understating of what kind of genetic testing is being made available to families, in particular to monitor the implementation of more detailed Array CGH tests, to feedback to our members.

Medical Research - Among other research projects, we will be supporting an application by Cambridge University and others for funding from the Medical Research Council for research into adults and ageing in genetically determined neurodevelopmental syndromes.

Collaborations - Unique will continue to play an active role in the UK and worldwide genetics and wider health community, including the European RCD network Eurochromnet. In the coming year Unique will help establish Eurochromnet as a registered French charity in order to apply for pan-European funding for Unique and its European partners.

Since the year-end, Unique staff has participated in the Eurordis (the European Rare Disorders) and the European Society of Human Genetics conferences. Staff members have also presented on, for example, "Patient Perspectives on array testing" at Guy's Hospital, London and will continue to provide our perspective to many more professionals.

We are also in discussions about the creation of an international patient registry with ISCA (International Standards for Cytogenomic Arrays Consortium) and continue our collaborations with DECIPHER (Database of Chromosomal Imbalance and Phenotype in Humans using *Ensembl* Resources) and Ecaruca (European Cytogeneticists Association Register of Unbalanced Chromosome Aberrations).

Guy's and St Thomas' NHS Hospital Trust in London sends a copy of our guide explaining Array CGH with every letter they send to patients about genetic testing.

Awareness and Fundraising

Aims and objectives

Awareness
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. Unique seeks opportunities to educate policy-makers about RCDs.

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 Alliance UK (formerly the Genetic Interest Group or "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.

Our CEO and information officers are invited to contribute to industry publications and conferences to share their knowledge with the medical profession.

Volunteers
Unique's network of volunteers who act as 'local contacts' for new and existing members in the UK and 19 countries worldwide also distribute the charity's awareness-raising posters and flyers to hospitals, social care departments, doctors' surgeries and special schools as well as helping with fundraising. As at the end of this year we had 156 local contacts, as well many more volunteers engaged in fundraising and awareness events. During the year we also welcomed two new trustees to the board.

Events
Key events in which our members participated were the 2009 London Marathon in which our eight runners raised £16,000, the Great North Run with 18 runners raising £11,000 and 13 runners in the 2009 BUPA 10K who raised £6,000.

Our volunteers also organised parachute jumps, sponsored walks, coffee mornings and raffles and many more. The Trustees are extremely grateful for all these wonderful efforts.

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2010

Performance in the past year 2009/10

Awareness
In 2009 Unique received a GlaxoSmithKline (GSK) IMPACT Award designed to "recognise and promote excellence in community healthcare". The benefits of that award filtered through this year in the form of advice to Unique on strengthening its current management plans and shaping its future aspirations, to ensure the Charity continues to make an invaluable contribution to community healthcare.

Winning the award helped raise our profile in the field of healthcare and GSK produced a short film about Unique's work and its staff.

In 2009 Unique was selected as one of Jeans for Genes' guest charities. This gave Unique a fantastic opportunity to raise awareness of RCDs within a nationally recognised campaign while a number of our families also featured in the media, covering their personal stories.

Unique continues to benefit from a Google Grant to channel traffic from Google searches to Unique's website.

This has increased traffic to Unique's website significantly. Many searches through Google for information on specific chromosome disorders will receive Unique as a primary search result.

Awareness and Indirect Family Support via Professionals
This year Unique continued to advise a wide range of professionals and colleagues in other support charities of the information we hold and the support we can offer. Over the past year our staff has given numerous presentations on the challenges faced by our families and our work in supporting them and regularly attend specialist conferences and meetings with awareness-raising information and displays. Examples include:

- presentation at the UK Genetic Testing Network's NHS commissioning conference on Array CGH at the Royal College of Pathologists;
- presentation to cytogeneticists and clinical geneticists at the West Midlands Regional Genetics Centre in Birmingham, the Wessex Regional Genetics Centre in Salisbury, the Kennedy-Galton Centre for Clinical Genetics in Harrow, at the joint meeting of Belfast and Dublin cytogeneticists and to geneticists and paediatricians at Guy's Hospital in London;
- teaching sessions on the challenges of living with a rare chromosome disorder in the family to medical students at University College London;
- hosting the annual conference of Eurochromnet, the European network of rare chromosome disorder support groups;
- contributing as expert patient representative on professional committees and working charity advisory panels (e.g. the Genetics Consortium Pre-implantation Genetics Diagnosis panel, Rare Diseases UK working group on Care, Information and Support to inform the new national strategy on rare disorders and the WellChild's Medical Research Grant Review Panel and Health Advisory Committee;
- providing awareness-raising at the annual conference of the British Society of Human Genetics and of the Association of Genetic Nurse Counsellors (our CEO and Information Officers are invited members of the British Society of Human Genetics.);
- interviews about RCDs and the work of Unique on TV and radio.

Plans for 2010/11

Fundraising will as already outlined be a priority for this coming year:

Recruitment - All forms of fundraising will be pursued vigorously in 2010/11, facilitated by a part-time fundraiser working on applications to trusts and foundations. Trustees are extremely grateful to existing staff for willingly going the extra mile to maintain the high standards of the charity, participate in fundraising and volunteer extra hours.

This year we will also focus on increasing our international fundraising, especially from the US to reflect the large number of members there, through tax-efficient giving.

Events - Our staff and volunteers kicked off the new financial year with a sponsored walk by families along Brighton seafront. This is to be followed by national and international Midsummer and Midwinter Meet Ups (coffee morning-style fundraisers at home) and of course the London Marathon, Great North, South and Manchester Runs, coast to coast walks, a Channel swim and many exciting other ideas by individual members.

Friends of Unique Appeal - To mark Unique's 25th anniversary last year, trustees asked members and well-wishers to form a loose-knit 'Friends of Unique' group.

The Friends of Unique's first initiative was launched in the latter part of this year – an appeal to increase voluntary donations from existing members. Unlike most support groups, Unique does not charge a membership fee (because of the need to maximise our public benefit and because of our need for data). The appeal launched in February has already raised a return of over £8 per £1 cost from the sample of members we have approached so far. This appeal will be rolled out to all members during the coming year but we are constrained by not having enough staff to do this work.

Financial Review

Income
Unique's income for 2009-10 was £268,799, an increase against its income of £186,202 in 2008-09.

Since Unique receives no guaranteed income from statutory sources, our income is inherently uncertain. Our primary source of unrestricted income (totalling £116,526 in 2009-10) has been donations by members and supporters and fundraising with some matched-funding received from or generated by our members, their friends, family and employers. We have also been fortunate to receive some unrestricted funding from charitable trusts and foundations. We are very grateful to all for their generous contributions, especially given the current climate.

Most of our restricted income (£53,923 in 2009-10) which covers the cost of our family support services (helpline, advice etc.) and information service (publications) came from charitable trusts.

Our Finance and Fundraising Executive Officer produces detailed monthly management accounts which are circulated to trustees and senior staff. Unique carries out a robust financial review before each quarter's 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.

Our biggest donors in 2009-10 (totalling £95,047) are listed below. We thank them for their support.

- 29th May 1961 Charitable Trust
- Brownless Charitable Trust
- Doris Field CT
- Dorothy Pamela Smith Trust
- Ernest Kleinwort Charitable Trust
- Eurogentest
- GSK IMPACT award
- Holbeck Charitable Trust
- Hugh Fraser Foundation
- Jeans 4 Genes
- K U Leuven R & D
- Sir Jules Thorn Charitable Trust
- Smith & Williamson Investment Management
- The B-CH 1971 Charitable Trust
- The Felicity Wilde Charitable Trust
- The Grocers Charity
- The Kathleen Laurence Charitable Trust
- The Lynn Foundation
- VICTA
- Worshipful Company of Butchers

Expenditure
Costs associated with core family services have been contained and in fact total expenditure was slightly reduced to £255,626 (from £276,214 in 2008-09), mainly due to the departure of one member of staff. There was a doubling in the value of donated services (including advertising costs via our Google Adwords grant) and donated consultancy fees from professionals. The main increases in expenditure were charges associated with online donations and fundraising event participation.

The Trustees are satisfied with the ratio of expenditure on core services, being 38% on Family Support Services and 37% on the Database and Publications. Governance costs account for a satisfactory 7% of expenditure.

Costs of generating funds
Unique's main costs associated with fundraising were: the part-time fundraiser's costs at £16,756; marathon and race bonds (£11,053); merchandise costs at £3,854 (Christmas card printing, banners, t-shirts used at fundraising events); online giving costs £3,160.

Fixed assets and investments
Unique does not have its own premises and all staff work from home. Its main assets are: cash on short and medium-term deposit (£129,894 on 31 March 2010) and tangible assets (mainly ICT hardware (£3,402)). Unique owns a signed Tracey Emin print, "Little Family", donated by the artist (valued at £700).

Since 2008, the Charity's policy has been to invest no more than £50,000 in any one financial institution to protect the charity's reserves from institutional failure. Investment of reserves is reviewed by Trustees at each quarter's management meeting, to ensure optimal returns. During the year we operated two Fixed Term Deposits with Birmingham Midshires and Bank of Ireland and have £30,000 and £50,000 invested respectively.

Activities to generate income
The sale of Christmas cards this year was successful with all designs selling out. Three new designs will be available in 2010 and thanks go to Sophie Sainty and staff for their input.

Unique is collaborating on a Springer publication in Germany on small supernumerary marker chromosomes which will provide royalties to Unique of 0.5% of sales.

Employees
Our employees are both our most important asset and our greatest cost area (£134,726 in 2009-10). With varied professional expertise and personal experience of RCDs in their families, they bring a synergy to the work of Unique.

Beverly Searle
Chief Executive Officer (CEO) has a background as a post-doctoral microbial geneticist. As mother of an adult daughter with a RCD, she has wide experience of working with social services and NHS statutory authorities. She leads Unique, ensuring its aims and objectives are met, as well as having overall responsibility for the day-to-day running and administration of the organisation, delivery of strategy, management and supervision of employees and operation of frontline services. She is involved in frontline specialist services to member families and professionals, as well as networking and awareness-raising of RCDs and the work of Unique among families, professionals and policy makers.

Julie Griffin
Finance & Fundraising Executive Officer (FFEO) was formerly a marketing manager at Lloyds Banking Group. Working part-time for Unique she is responsible for management and company accounts, oversees the day-to-day financial controls, and coordinates members' fundraising activities. Julie lost her daughter to a RCD.

Prisca Middlemiss
Senior Information Officer (SIO) is a medical journalist . She directs the research and production of family-friendly Chromosome Disorder Guides and develops professional contacts in the UK and abroad. Prisca lost a son to a RCD.

Craig Mitchell
Operations Manager was previously operations manager at a media and telecoms business and is parent of a child with a RCD. He is responsible for the day-to-day operational management of the charity and has become Company Secretary.

Sarah Wynn
Information Officer . Her husband carries a balanced chromosome translocation but was unaffected until the couple suffered multiple miscarriages when trying to have babies of their own. Their oldest child is also a carrier and unaffected by the balanced chromosome translocation. Formerly a post-doctoral geneticist at Imperial College of Medicine and the National Institute of Medical Research, Sarah researches and compiles our Chromosome Disorder Information Guides and provides advice to members requiring specialist information on genetic testing.

Marion Mitchell
Family Support Officer from a customer services background and the mother of a teenager with RCD, she is the day-to-day point of call for families. She sends our welcome packs, monitors our online groups and sources information for the Magazine.

During the year the Charity employed the services of a short-term fundraiser, Norah Laurie, whom the Trustees thank very much for all her hard and effective work in increasing small grant income.

The Trustees are very grateful to Satnam Juttla, Information Officer who left her position with Unique at the end of the last financial year, for all her work during her employment with the charity, especially the insight and understanding she brought to communication with families from Black and Minority Ethnic backgrounds. The loss of Satnam's particular talents brought renewed focus to our wish to see greater diversity among all Unique stakeholders and efforts continue to bring this about.

Pensions
Unique does not make pensions provisions for employees, other than to provide access to a Stakeholder pension.

Reserves Policy
In 2009 the trustees looked at predicted income and the charity's planned operating needs and revised the previous policy on reserves to allow greater flexibility, permitting the use of general funds to cover income fluctuations against budget. Provided that at all times services to member families during the year are protected, then reserves may fall to a level sufficient to cover contractual liabilities (mainly relating to employees), maintain required equipment, provide working capital and ensure quality service delivery, This policy remains in place for the new financial year.

In the previous financial year (2008-09), facing falling income, the charity dipped into its general funds to finance normal operational costs to minimum service standards, At 31 March 2009 unrestricted funds stood at £83,835. We had predicted a continued need to draw on free reserves if the quality and quantity of core services were to be maintained against a possible backdrop of falling revenue. As it was, the buoyancy of receipts from all quarters coupled with the customary extra unpaid hours from staff meant that Unique delivered exemplary services to all comers last year - however at some cost to the charity's available reserves.

We did increase the sum set aside for the Listening Ear helpline core activity and, more pleasingly, the generosity of grant makers meant that we finished a year with £25,890 in the bank earmarked for specific specialist services, principally for the delivery of "mini-conference" chromosome disorder Study Days in 2010 that have proved so successful on so many levels with families and researchers.

Overall, total funds held in reserve rose during the year by £13,173 to £135,460 but free reserves fell by £16,802 to £67,033. At this minimal level, trustees and senior managers set once again a very conservative budget and are ready to cut back swiftly, even on core services, if income in 2010-11 falls below the forecast level.

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:

- **Trevor Searle**, for his generous donation of expertise and time to Unique's database, website and online capabilities.
- **Patrick Griffin**, for his expertise and time spent supporting staff with their ICT.
- **Professor Maj Hulten**, for her countless hours checking and verifying Unique's Chromosome Disorder Guides.
- Other expert medical professionals around the world who verify and translate Unique's publications, offering advice and expertise willingly and with great enthusiasm.
- **SupaStorage**, Wimbledon, for the donation of storage space.
- **Carey Hunt**, graphic designer, for using her professional creative skills to design the excellent Unique publications.
- **Cancer Research UK,** for providing training in fundraising and database management.
- **Caroline Marrows** of LloydsTSB, for acting as facilitator and stimulating discussions at our recent strategy review day.
- **Farrer & Co** Solicitors, who offered their splendid offices in Lincoln's Inn as a venue for meetings.
- 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.

Structure, Governance and Management

Corporate and social responsibility and sustainability
Unique's policy is to seek to reach all members of our communities who may be affected by a RCD irrespective of background, race, religion or culture. We are an equal opportunity employer.

Staff work from home and use teleconferencing as much as possible, minimising our organisation's carbon footprint.

Management of risk
The major risks to which the charity could be exposed, as identified by trustees and senior staff, were considered and recorded in an updated risk register in 2009 with contingency plans in place as operating conditions and/or performance change. The charity's position is kept under review and discussed in detail at each meeting of the trustees as well as at other times.

Compliance and training
Given the importance to our work of personal and sensitive medical data concerning member families, staff and trustees are aware of the requirements of data protection law and will receive intensive training in data protection in the coming year.

In 2009-10 various staff members received training in fundraising and leadership and will receive further fundraising training as well as training in bereavement counselling in the coming year.

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

All staff and trustees are CRB checked, as are those volunteers whose work brings them into direct contact with our member children and vulnerable adults.

Governance
The board of trustee-directors of the charity met regularly throughout the year with the senior management team to define strategy and monitor performance. We made use, too, of conference call facilities and email to discuss specific matters between ourselves as and when appropriate.

Registered members of the company limited by guarantee and others with an interest in Unique are invited to attend the Annual General Meeting and kept informed by the Company Secretary.

A review of the governance and management structures of the charity is ongoing to ensure optimal use of resources. 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. The trustees are keen to ensure that management decisions are taken in an open and collaborative spirit, ensuring that all staff feel involved and able to contribute their expertise.

During the year Gemma Mitchell, Eleanor Fiske and Sophie Sainty recorded meeting minutes and we thank them sincerely.

Trustee recruitment
Trustees are recruited by advertising through the members' magazine, appropriate media and personal contacts. We continually seek to bolster our Board of Trustees with professional experience in accountancy, charity fundraising, PR and marketing as well as those who can represent the perspective of families. We look for applicants from a diverse range of ethnic and social backgrounds.

We were delighted to welcome two new trustees in 2009-10 and continue to seek additional trustees to contribute to the diversity of our Board.

Potential trustees are interviewed by one or more Trustees and the CEO, who then make a recommendation to the Board for election by majority vote. Candidates are provided with full documentation on the Charity's activities and plans and on his/her role and responsibilities as a Trustee and company director. A new trustee is invited to contact other Board members and staff for more information. Appointments are formalised only after CRB (or in future Independent Safeguarding Authority) checks are completed.

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2010

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, balancing modest fundraising revenues with our fixed and discretionary costs. However trustees note that current service levels cannot be provided to projected increased membership in future if future income does not increase.

The Board of Trustees sets the Charity's strategic direction, monitors the delivery of the Charity's objectives, upholds its values and governance, and guides, advises and supports the Chief Executive Officer who leads the staff towards achieving the Charity's vision and purpose. It is the policy of Unique that a majority of trustees should have a family member with a RCD.

The Trustees who served during the year are detailed on page 1 of this report. Brief biographies follow of trustees serving at 31 March 2010.

Edna Knight - Life President founded the Charity in 1984 as the Trisomy 9 Support Group after the birth of two daughters with chromosome 9 disorders. She soon expanded the charity to include families affected by any rare chromosome disorder. With her 25 years helping families affected by RCDs, she is an inspiration and a beacon to our trustees and staff. Edna is Unique's local area contact for Middlesex.

Gillian Manvell - Chairman and parent of a young adult with a rare chromosome disorder, has been a member of Unique's management committee and a trustee for over 17 years. With a business background, she runs an award-winning educational technology company and has held a wide variety of voluntary offices since the birth of her children. Gill is Unique's local area contact for South London.

Sophie Sainty - a member of Unique since the birth of her son with a rare chromosome disorder nine years ago, was appointed a Trustee in December 2009. Formerly a solicitor in the City in the field of commercial and regulatory law, she has also had previous experience as a Trustee and Company Secretary in the charitable sector. She is a school governor and is Unique's local area contact for Hammersmith, Fulham and Chiswick.

Michael Toothill - has spent his professional life working in the not-for-profit sector and works in customer relationship management for Cancer Research UK. He became involved in Unique when he provided the Charity with advice on strategy, CRM and database management through the Pilotlight programme. He was appointed a Trustee of Unique in January 2010.

David Williams - is a senior banker and marketing strategist with 20 years experience in the UK Financial Services industry. Currently Head of SME Marketing in the Commercial Division of Lloyds Banking Group, David joined Unique as a Trustee in 2008 to support the Management Team with the strategic development of the organisation.

In January 2010, **Eleanor Fiske** resigned as a trustee of Unique. She joined the group on the birth of her son in 2001 and later, offered her services as minutes secretary. Eleanor saw through conversion of the original charity to charitable company, becoming a trustee and its first Secretary. To the benefit of Unique, for 6 years she shared unstintingly, in meetings and behind the scenes, both her legal expertise and experience as parent of a child with complex needs. Eleanor's perspicacity, hard work, loyalty and encouragement underpinned our governance and we thank her, on behalf of all Unique's beneficiaries, for the invaluable contributions she made.

Statement of Responsibilities of The Trustees

The trustees are required to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and the incoming resources and application of resources, including the net income or expenditure, of the charity for the year. In preparing those financial statements the trustees are required to:

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

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

The trustees confirm that to the best of their knowledge there is no information relevant to the audit of which the auditors are unaware. The trustees also confirm that they have taken all necessary steps to ensure that they themselves are aware of all relevant audit information and that this information has been communicated to the auditors.

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

Auditors

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

Approved by the trustees on 21 October 2010 and signed on their behalf by

E. M Knight

Edna Knight - Trustee (Life President)

Gillian Manvell - Trustee (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 2010 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 Chapter 3 of Part 16 of the Companies Act 2006. 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 the company for the purposes of company law) responsibilities for preparing the Trustees Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and for being satisfied that the financial statements give a true and fair view are set out in the Statement of Responsibilities of the Trustees.

We have been appointed auditors under the Companies Act 2006 and section 43 of the Charities Act 1993 and report to you in accordance with those Acts. 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, have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, and have been prepared in accordance with the Companies Act 2006. We also report to you whether in our opinion the information given in the Trustees Annual Report is consistent with those financial statements.

In addition we report to you if, in our opinion, the charity has not kept adequate accounting records, if the charity's financial statements are not in agreement with the accounting records and returns, if we have not received all the information and explanations we require for our audit, or if certain disclosures of trustees' remuneration specified by law are not made.

We read the Trustees Annual Report and consider the implications for our report if we become aware of any apparent misstatements within it.

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 2010 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 2006 and the Charities Act 1993; and

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

Rob Wilson

Date: 28 OCTOBER 2010

Robert Wilson ACA
(Senior Statutory Auditor)
For and on behalf of:

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

Rare Chromosome Disorder Support Group

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

For The Year Ended 31 March 2010

	Note	Restricted £	Unrestricted £	**2010 Total £**	2009 restated* Total £
Incoming Resources					
Incoming Resources from Generated Funds:					
Voluntary Income	2	-	141,326	**141,326**	80,995
Activities For Generating Funds	3	-	71,147	**71,147**	59,294
Investment Income		-	2,403	**2,403**	8,364
Incoming Resources from Charitable Activities:	4				
Family Support Services		15,925	-	**15,925**	18,120
Information Services		37,998	-	**37,998**	19,429
Total Incoming Resources		53,923	214,876	**268,799**	186,202
Resources Expended					
Costs of Generating Funds:					
Fundraising Costs		-	43,120	**43,120**	34,730
Merchandise Costs		-	3,854	**3,854**	3,526
Charitable Activities:					
Family Support Services		14,439	81,742	**96,181**	130,911
Information Services		16,593	77,733	**94,326**	83,189
Governance Costs		-	18,145	**18,145**	23,858
Total Resources Expended	5	31,032	224,594	**255,626**	276,214
Net Incoming Resources Before Gains & Transfers		22,891	(9,718)	**13,173**	(90,012)
Transfers Between Funds		(453)	453	**-**	-
Net Movement in Funds	6	22,438	(9,265)	**13,173**	(90,012)
Reconciliation of Funds					
Total Funds Brought Forward		3,452	118,835	**122,287**	212,299
Total Funds Carried Forward		25,890	109,570	**135,460**	122,287

* Charitable Activities were previously reported under a single heading (Family Support Services). In 2009/10 Charitable Activites were split into two headings (Family Support Services & Information Services). The 2008/9 comparatives have been restated to ensure consistent analysis of income and expenditure.

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 2010

	Note	£	2010 £	2009 £
Fixed Assets				
Tangible Fixed Assets	9		**3,402**	1,593
Investments	10		**700**	700
			4,102	2,293
Current Assets				
Stock	11	**340**		1,970
Debtors	12	**8,067**		12,156
Cash at Bank and in Hand		**129,894**		112,275
		138,301		126,401
Creditors: Amounts Due Within 1 Year	13	**6,943**		6,407
Net Current Assets			**131,358**	119,994
Net Assets	14		**135,460**	122,287
Funds	15			
Restricted Funds			**25,890**	3,452
Unrestricted Funds:				
Designated Funds			**42,537**	35,000
General Funds			**67,033**	83,835
Total Funds			**135,460**	122,287

Approved by the trustees on 21 October 2010 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 2010

1. Accounting Policies

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

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

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

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

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

Computer equipment	4 years

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.

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

2. Voluntary Income

	Restricted £	Unrestricted £	**2010 Total £**	2009 Total £
Grants > £1,000				
Glaxo Smith Kline	-	25,000	**25,000**	-
The Grocers' Trust	-	9,428	**9,428**	-
Hugh Fraser Foundation	-	3,000	**3,000**	-
Smith & Williamson	-	2,000	**2,000**	-
Health Foundation	-	-	**-**	6,825
Grants < £1,000	-	4,900	**4,900**	500
Donated Goods / Services *	-	50,324	**50,324**	31,045
General Donations	-	22,155	**22,155**	16,394
Corporate Donations	-	5,917	**5,917**	12,121
Gift Aid	-	13,328	**13,328**	8,921
Give As You Earn	-	1,296	**1,296**	1,827
Overseas Donations	-	3,373	**3,373**	2,729
Pyramids	-	605	**605**	633
Total Voluntary Income	-	141,326	**141,326**	80,995

* Donated services consist of the following:	**2010 Total £**	2009 Total £
Google AdWords (free web advertising)	**10,559**	5,660
Website & database design, development & maintenance	**4,970**	6,000
Professional verification of information in the charity's publications	**20,800**	12,740
Translation of charity's publications	**2,675**	2,925
Creche services	**-**	1,200
Professional services	**1,200**	900
Secretarial services	**320**	300
IT support	**9,800**	1,320
Total Donated Services	**50,324**	31,045

Voluntary income has increased significantly year on year as a result of the additional resource expended through the employment of a consultant fundraiser.

Donated Google AdWords is proving extremely successful in driving more activity to our website and allowing families more access to information.

Donated Professional verification of publications has increased as a result of the more complex Information Guides now being produced on MicroArrays.

3. Activities For Generating Funds

	Restricted £	Unrestricted £	**2010 Total £**	2009 Total £
Fundraising Activities	-	66,648	**66,648**	54,188
Christmas Card & Merchandise Sales	-	4,499	**4,499**	5,106
Total Activities For Generating Funds	-	71,147	**71,147**	59,294

4. Incoming Resources From Charitable Activities

	Restricted £	Unrestricted £	**2010 Total £**	2009 (restated) Total £
Family Support Services:				
Grants				
VICTA	6,125	-	**6,125**	5,950
ACT Training Grants	-	-	**-**	319
Anonymous	-	-	**-**	1,000
Steel Charitable Trust	-	-	**-**	1,000
Lynn Foundation	500	-	**500**	-
Felicity Wilde	3,000	-	**3,000**	-
B-CH 1961 Charitable Trust	500	-	**500**	-
29 May 1961 Charitable Trust	5,000	-	**5,000**	-
Dorothy Pamela Smith Trust	800	-	**800**	-
Donations	-	-	**-**	2,967
Conference Income	-	-	**-**	6,604
Fundraising Activities	-	-	**-**	280
Information Services:				
Grants				
K U Leuven R&D - Eurogentest	3,072	-	**3,072**	513
Kathleen Laurence	1,000	-	**1,000**	-
R S Brownless	150	-	**150**	-
Grocers Trust	25,572	-	**25,572**	-
Jeans 4 Genes	5,000	-	**5,000**	-
Charles Hayward Foundation	-	-	**-**	10,000
Gatwick Airport Pantomime Society	-	-	**-**	8,500
University of Oxford	-	-	**-**	416
Donations	3,204	-	**3,204**	-
Total Charitable Activities	53,923	-	**53,923**	37,549

5. Total Resources Expended

	Fundraising Costs * £	Merchandise Costs £	Family Support Services £	Information Services £	Governance Costs £	Support Costs £	**2010 Total £**	2009 Total £
Staff Costs (Note 7)	16,756	200	54,524	54,936	8,310	-	**134,726**	142,951
Training	58	-	162	-	86	-	**306**	645
Postage & Distribution	829	603	14,545	528	62	467	**17,034**	20,392
Printing & Design	165	2,876	13,421	1,148	238	-	**17,848**	22,192
Stationery	187	129	2,185	1,434	49	39	**4,023**	4,302
Subscriptions, Licences & Charges	12,447	-	343	1,093	388	221	**14,492**	10,701
Travel & Subsistence	339	46	465	2,487	1,111	-	**4,448**	6,104
Room Hire & Event Costs	-	-	-	1,134	6	-	**1,140**	25,391
Equipment & Software	72	-	671	78	1,023	-	**1,844**	2,778
Books & Publications	-	-	-	75	-	-	**75**	100
Home Office Costs	559	-	1,644	1,020	275	102	**3,600**	3,960
Conference Costs	-	-	-	-	-	-	**-**	234
Website & Database Development	-	-	5,413	-	-	-	**5,413**	6,444
Advertising	10,559	-	-	-	-	-	**10,559**	5,660
Insurance	-	-	-	-	2,924	-	**2,924**	2,637
Audit & Accountancy	-	-	-	-	2,903	-	**2,903**	2,818
Consultancy	700	-	1,960	29,845	770	-	**33,275**	17,885
Depreciation	-	-	300	-	-	746	**1,046**	880
Profit on Disposal of Fixed Assets	-	-	-	-	-	(38)	**(38)**	-
Miscellaneous Costs	-	-	-	-	-	8	**8**	140
Sub-Total	42,671	3,854	95,633	93,778	18,145	1,545	**255,626**	276,214
Allocation of Support Costs	449	-	548	548	-	(1,545)	-	-
Total Resources Expended	**43,120**	**3,854**	**96,181**	**94,326**	**18,145**	**-**	**255,626**	276,214

* We invested in a consultant fundraiser to support the increased activity in applying for Trust funding, and it is noted that a great deal of personal time has been donated by staff on activities such as Governance, Information Services and Family Support Services to ensure that we deliver the same standard of support for all our families.

6. Net Movement in Funds

This is stated after charging:

	2010	2009
	£	£
Depreciation	**1,046**	880
Trustees' indemnity insurance	**1,378**	1,321
Trustees' reimbursed expenses	**-**	102
Auditors' remuneration:		
▪ Statutory Audit	**2,644**	2,587
▪ Grant Audits	**259**	231

7. Staff Costs and Numbers

Staff costs were as follows:

	2010	2009
	£	£
Salaries and Wages	**118,003**	129,972
Social Security Costs	**10,718**	11,843
Freelance Staff	**6,005**	1,136
	134,726	142,951

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

	2010	2009
	No.	No.
Average number of employees (full-time equivalent)	**4.37**	4.97

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 2009	**4,870**
Additions in year	**3,107**
Disposals in year	**(505)**
At 31 March 2010	**7,472**
Depreciation	
At 1 April 2009	**3,277**
Charge for the year	**1,046**
Disposals in the year	**(253)**
At 31 March 2010	**4,070**
Net Book Value	
At 31 March 2010	**3,402**
At 31 March 2009	1,593

10. Investments

	2010	2009
	£	£
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

	2010	2009
	£	£
Merchandise	**340**	1,970

12. Debtors

	2010	2009
	£	£
Prepayments	**4,839**	7,531
Other Debtors	**3,228**	4,625
	8,067	12,156

13. Creditors : Amounts Due Within 1 Year

	2010	2009
	£	£
Accruals	**3,905**	3,324
Other Taxation & Social Security	**3,038**	3,083
	6,943	6,407

14. Analysis of Net Assets Between Funds

	Restricted Funds	Unrestricted Funds	**Total Funds**
	£	£	**£**
Tangible Fixed Assets	-	3,402	**3,402**
Investments	-	700	**700**
Current Assets	25,890	112,411	**138,301**
Current Liabilities	-	(6,943)	**(6,943)**
Net Assets at 31 March 2010	**25,890**	**109,570**	**135,460**

15. Movements in Funds

	At 1 April 2009 £	Incoming Resources £	Outgoing Resources £	Transfers Between Funds £	**At 31 March 2010 £**
Restricted Funds					
VICTA	-	6,125	(5,439)	-	**686**
SAFE Fund	1,134	-	(681)	(453)	**-**
Eurogentest Fund	2,318	3,072	(2,181)	-	**3,209**
Helpline	-	9,000	(9,000)	-	**-**
Information Project	-	1,150	(1,150)	-	**-**
Dorothy Pamela Smith Trust	-	800	(300)	-	**500**
Study Days	-	33,776	(12,281)	-	**21,495**
Total Restricted Funds	3,452	53,923	(31,032)	(453)	**25,890**
Unrestricted Funds					
Designated Funds:					
Listening Ear Fund	35,000	-	-	7,537	**42,537**
Total Designated Funds	35,000	-	-	7,537	**42,537**
General Funds	83,835	214,876	(224,594)	(7,084)	**67,033**
Total Unrestricted Funds	118,835	214,876	(224,594)	453	**109,570**
Total Funds	122,287	268,799	(255,626)	-	**135,460**

Purposes of Restricted Funds

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
Helpline	To fund the costs of the helpline.
Information Project	To fund the information project.
Dorothy Pamela Smith Trust	To fund the purchase of computer equipment.
Study Days	To fund the costs of the Study Days programme.

Purpose of Designated Fund

Listening Ear Fund	The trustees have designated a further £7,537 from general funds to the charity's 'Listening Ear' project, bringing the total designated fund to £42,537. 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 2010-11. It is hoped that with additional funding from a sponsor, the service can be developed further through the recruitment and training of additional staff and enhancement of current ICT capability.