Company no. 5460413
Charity no. 1110661

Rare Chromosome Disorder Support Group

Report and Audited Financial Statements

31 March 2011

Rare Chromosome Disorder Support Group

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For The Year Ended 31 March 2011

Rare Chromosome Disorder Support Group

Reference and Administrative Details

For The Year Ended 31 March 2011

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:

Sophie Sainty	Chairman, elected 14 January 2011
Gillian Manvell	Resigned as Chariman 14 January 2011
Edna Knight	Founder, Life President
Sally Cohen	(appointed 25 October 2010)
Michael Toothill	(resigned 6 August 2010)
David Williams	(resigned 20 May 2010)

Company Secretary	Craig Mitchell
Principal Staff	Beverly Searle — Chief Executive Officer Craig Mitchell — Operations Manager Marion Mitchell — Family Support Officer Prisca Middlemiss — Senior Information Officer Sarah Wynn — Information Officer Julie Griffin — Finance & Fundraising Executive Officer (resigned 11 February 2011)
Chief Medical Advisor	Professor Maj Hulten
Patrons	Professor Dian Donnai, UK Professor Jean-Pierre Fryns, Belgium Professor Judith Hall, Canada Professor Albert Schinzel, Switzerland
Bankers	Charities Aid Foundation Kings Hill West Malling Kent ME19 4TA Bank of Ireland PO Box 27 One Temple Quay Bristol BS99 7AX 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 2011

FAQs: What are rare chromosome disorders?
Chromosome disorders are genetic disorders, present in a person's makeup at birth, which can lead to medical, intellectual, social, behavioural, reproductive or other problems and disabilities.

Chromosome disorders are caused by extra, missing or re-arranged parts of an individual's chromosomes. Chromosome disorders can be inherited from a parent with a chromosome disorder or arise spontaneously.

The chromosome disorders covered by Unique's work are rare, that is, each disorder has no more than a few known cases worldwide. Some chromosome disorders are so rare that they are actually 'unique', while many others may be shared with just a handful of people in the world. Well-known chromosome disorders, like Down's and Williams, are well described in medical literature and have their own specialist charities.

What are the consequences of chromosome disorders?
Children and adults with chromosome disorders may be unable to walk or talk and have complex behavioural, learning or communication difficulties, as well as a spectrum of medical disorders. They will have a very demanding lifelong emotional and physical impact on their families. Family breakdown can often result. The problems they face are exacerbated when doctors and other professionals do not have the specific knowledge to answer the many associated questions.

How common are chromosome disorders?
Individually, chromosome disorders are indeed very rare but collectively, they are common.

- At least one in every 200 babies is born with a rare chromosome disorder although many may not be affected in a visible way, perhaps only discovering they have a chromosome disorder later in life through investigation of fertility complications or on the birth of a disabled child.
- At least one in every 1,000 babies will be disabled or have significant symptoms from birth or early childhood.

These statistics are set to rise rapidly as many more babies (and previously undiagnosed adults and children) can be checked for chromosome disorders using the latest testing techniques.

How much do doctors know?
Even among the more common chromosome disorders, it is likely that professionals like GPs, social workers or hospital consultants never will have come across anyone with the same disorder before.

How do you test for chromosome disorders?
DNA is present in almost every cell in our bodies and is bundled into packages called chromosomes, themselves containing the genes that determine everything from hair colour to medical and developmental traits. Typically people have 46 chromosomes: we inherit one set of 23 chromosomes from our mother and one set of 23 chromosomes from our father. DNA is passed in this way from parent to child and contributes to development and health. Those with chromosome disorders may have fewer or more than 46 chromosomes or extra/rearranged/deleted segments of chromosomes.

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2011

Genetic analysis over the past thirty or more years involved karyotyping (viewing chromosomes down a microscope) which detected larger duplications/deletions or other rearrangements of chromosomes or segments of chromosomes. "Array CGH" (microarray-based comparative genomic hybridization analysis) now allows for smaller and more complex chromosome imbalances to be identified. The newest form of analysis being introduced, "next generation sequencing", will diagnose still smaller chromosome disorders, some affecting just one or 2 genes, which could not be seen under previous analytical techniques. Many children and adults with special needs currently labelled "undiagnosed" are likely to be diagnosed with chromosome disorders as a result.

The trustees present their report and the audited financial statements for the year ended 31 March 2011.

Chairman's Statement

Unique is the UK's only charity supporting the families of children born with rare chromosome disorders and is a world leader in the field.

Up to 60,000 people in the UK have disabilities or medical problems due to rare chromosome disorders – but many such children and adults are as yet undiagnosed.

Most families are devastated by the birth or diagnosis of their child with such chromosome disorders. Depending on the genetic material involved, the consequences for the individual can range from severe and life-limiting medical problems, lifelong complex disabilities and learning disabilities through to fertility problems/recurrent miscarriages in normal adults.

The first questions parents ask about the diagnosis are how will it affect their child, how long will they live, will they walk, talk, read, write, etc. Each individual disorder is rare, so there are few sources of information to say how any particular child or adult might be affected. More often than not professionals have no prior knowledge or information to give to parents and cannot shed light on what the future holds. This is where Unique comes in as the world's leading source of information on rare chromosome disorders.

Our mission is to inform, support and alleviate the isolation of anyone affected by a rare chromosome disorder and to raise public awareness.

The aims and objectives of the charity are, for the public benefit, to promote the relief of people suffering from rare chromosome disorders by:

1. Providing **expert information** for parents and professionals: 136 specific chromosome disorder guides and a unique database that documents the characteristics and case histories of 10,000 people with rare chromosome disorders, a specialist website attracting 9,000 new visitors per week and a magazine containing practical ideas for families living with chromosome disorders.

2. Offering **practical support** through a listening ear service, which receives over 1,100 phone, postal and emai**l** enquiries per month, often the first point of contact for the distressed parents of a recently diagnosed child. It provides a family matching service, linking those living with similar conditions, to share experiences and information and offer each other invaluable mutual support.

3. Developing a **network for families and professionals,** e.g. 156 volunteer Local Contacts who are able to empathise with and support families of newly diagnosed children, signposting them to local services and other resources. Unique's conferences and study days bring together families and professionals to develop understanding of specific disorders and stimulate informal support networks between them.

Thus Unique is a lifeline to over 8,000 member families (including my own on the birth of my son) and, indirectly, to thousands of other families and professionals throughout the world who access our free publications through our website without joining Unique. Our services are freely available to any individuals and families affected by a rare chromosome disorder, wherever they live. We aim to serve the general public by raising awareness of and providing understandable information about the disorders, freely available on our website.

Unique is respected by geneticists and doctors worldwide for the breadth of information we hold on chromosome disorders and for our understanding of their implications.

Despite Unique's invaluable high-quality research, publications and helpline, it receives no government funding and relies entirely on charitable trusts, on the generosity of companies, members' donations and fundraising activities.

This year, Unique has seen:

- very rapid membership growth due to a huge increase in rare chromosome disorder (chromosome disorder) diagnoses, and
- a much more competitive and challenging funding environment caused by the global and UK economic situation.

In future, to ensure that Unique can continue to help the thousands of families and medical professionals that call on its help every year, Unique will need to:

- commission a more sophisticated database to store our bank of chromosome disorders case histories and characteristics in order to improve analysis, understanding and sharing amongst the steeply increasing numbers of people who are being diagnosed,
- expand its family support team to meet the needs of its increasing membership, and
- underpin those two aims with greater funding and improved infrastructure.

This annual report will tell you more about the invaluable work done by Unique. This work would not be possible without the dedication of our staff, volunteers, members and funders to whom the Trustees pay homage on behalf of members and other affected families worldwide. Our particular thanks to three outgoing members of our team: Trustees David Williams and Michael Toothill for their dedication to Unique and Julie Griffin for her long and loyal service as Finance Officer of Unique.

Public Benefit

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.

Sophie Sainty, Chairman of Trustees
October 2011

Rare Chromosome Disorder Support Group

Report of the Trustees

For The Year Ended 31 March 2011

Strategy

Planning

The Charity's long-term aim is to make families feel less isolated, better informed and more supported, to look after and support their children.

This year marks the end of Unique's 2006/2011 plan with the following results:

- **extend the network of local contacts and increase the number and types of volunteers to develop awareness-raising and fundraising:** from 120 local contacts to 156 today.
- **ensure Unique's work is well respected among professionals and its reputation remains outstanding:** see examples of our professional recognition on page 8; awareness of Unique has increased among all stakeholders evidenced by the increasing number of referrals by professionals; Unique has participated in 50 research projects in that period.
- **improve Unique's engagement with the families of adults and older people affected by chromosome disorders 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.** Despite the high cost of postage, we continue to publish our magazine in print in order to reach those without internet access. During the period we recruited a BME-focused Information Officer and launched our "Beating the Isolation" strategy.
- **recruit staff (information officer to share specialist staff overload, operations manager to support frontline staff in meeting objectives and fundraiser to underpin increase in member services), improve our internal ICT and database management and review branding/PR to maximise awareness of Unique and its role:** Sarah Wynn, an experienced post-doctoral geneticist joined as information officer in 2007, Craig Mitchell joined the team as operations manager in 2008 and since 2009, Unique has contracted the services of a part-time fundraiser to develop income from charitable trusts. IT hardware, especially security software, has been upgraded. Commissioning of the new database and a PR and branding review by agency Red C are in train. In 2010 our Pilotlight PR/branding mentor became a trustee.

During 2011 we will set out our strategy and objectives for the next 3 years in greater detail. The basis will be:

- meeting the needs of a membership likely to double in size whilst retaining high-quality personalised services
- broadening our support of teenage and adult members
- increasing social networking support
- raising awareness of chromosome disorders and the challenges faced by those affected amongst:
    - families not already accessing our services, including those from communities that are hard to reach
    - non-genetics medical professionals
    - government circles and the public
- rebuilding and updating the database and establishing a rolling update of members' data
- producing another 80 chromosome disorder information guides to cover more disorders and general issues of general relevance to our members
- holding regular study days/weekends and members' conferences every 2 years
- meeting the information and support challenges of a myriad of novel diagnoses due to the rapid roll out of ever more sophisticated genetic analysis.

and, necessarily underpinning all of that:

- building a stable funding base for our work.

Finances

Unique is a small charity working with 3 full time and 3 part time employees; we run extremely cost effectively and punch well above our weight.

Expanding membership: We are expecting a steep rise in our client group. Unique's membership has almost doubled over the past 5 years. This year was a record, with 800 new members joining. The average for the 5 years prior to this year was 544 new members per year.

The rise is mainly due to improved techniques leading to better diagnosis of chromosome disorders, including smaller microdeletions and microduplications that were previously undetected. Our survey this year of UK genetics centres leads us to expect the numbers diagnosed with chromosome disorders to double within the next 3 years and thus, the number of potential Unique members.

Membership of Unique is free. Unique receives neither statutory grants nor government funding despite its evident public benefit, so it relies heavily on charitable grants and donations.

Reaching more and more members does present a serious challenge. In 2005 we served 4,500 families on an income of £216,000; 6 years later, on £265,000, we have 60% more families and need to generate far more income to ensure they receive the same excellence of service.

This year, Unique's total income from grants, donations and fundraising was sustained (taking into account changes to the declaration of donated services). Members continued to make a significant contribution through their fundraising, despite the recession. In 2010/11 our members participated in the 2010 London Marathon - 5 runners raised over £8,000, the Great North Run with 18 runners raising just over £13,000. Our staff, volunteers and their disabled children carried out a sponsored walk along Brighton seafront. Others organised parachute jumps, sponsored walks, coffee mornings and many more events. The Trustees are grateful for all these wonderful efforts. In 2011/12 we will be helping members to join in and/or organise many more such events.

Funding from major grants and trusts increased at the year-end due to the work of a major grant specialist fundraiser we hired this year. We focused on increasing our international fundraising by enabling tax-efficient giving from the US to address the costs of services to our US members. We made a pilot appeal to 100 US families for donations and obtained a proxy s.501(c) (3) registration to facilitate tax-efficient giving by US donors but neither has so far resulted in significant returns.

A 25th anniversary appeal for increased donations from existing UK members raised voluntary income to a level slightly above the previous year. In 2011 we will be organising an event for members to honour their fundraising contributions so far and encourage further efforts.

Planning for 2011/12: With the economy still expected to stagnate and cuts expected to affect UK families for many more years, we do not expect any big rise in income from current sources in the coming year. We will continue to focus on increasing income from charitable trusts and major donors. We are considering a voluntary membership fee to create a new, stable source of income, however this must be balanced against the danger of deterring potential members and reducing members' fundraising activities.

The key new costs for 2011/12 relate to increasing capacity. We plan firstly, to recruit two additional family support staff so that we can meet the needs of all new members and secondly, to commission a new database system with future capacity built in to manage better our chromosome disorder data, create new opportunities for research and simultaneously, to respond to far more inquiries from families and professionals.

Meeting the challenges faced by families and professionals

Unique's aim is to reduce the isolation caused by a chromosome disorder diagnosis, collecting and sharing information among affected families, providing support and improving public awareness of its effects.

1. Expert information

Our chromosome disorder database: Unique has built up a database of medical, developmental and behavioural histories of more than 10,000 individuals with rare chromosome disorders, compiled over 15 years. There is no other in-depth database like Unique's in the world.

This resource provides direct support to our families by informing them about the case histories of similarly affected children and enables us to match families.

The database gives vital information (anonymously, to maintain confidentiality) to health and other professionals who use it for care management, educational and research purposes, ensuring that patients are screened, monitored and treated appropriately to their disorder. Our own staff uses the database to provide information to health professionals and families, tailored to their requests.

Initially designed 15 years ago, the current database system, housing details of members' chromosome disorders, has been tremendously effective but now needs replacing if we are to cope with medical and scientific changes and manage the increasing volumes of data which Unique holds.

A new system for the storage and management of our chromosome disorder data allowing secure, real-time multi-user access, will enable Unique's small staff to work many times faster, with up-to-the-minute records and without the duplication of activity that is required at the moment. It will speed up response times to the hundreds of enquiries about rare chromosome disorders received every month and spread the load of answering queries between staff. This will be of particular and immediate benefit when supporting clinicians who are counselling parents of affected children and planning their care and who frequently require information at short notice. The new database will streamline the compilation of the chromosome-specific guides (below).

In 2010/11 we commissioned a requirements specification for the new database. Now this is going out to tender and will be used to seek funding in 2011/12. Building the new system is expected to take at least a year. A follow-on update of all members' data will require the recruitment of a database curator. The work is dependent upon success in obtaining firstly, new funding for the database design and implementation and secondly, funds to cover the costs of the mailing, processing and verification of new data. This project is a key funding objective for 2011/12.

Our chromosome disorder information guides: The database is the source of our ever-growing library of chromosome disorder information guides. These information guides cover the published medical literature on chromosome disorders supplemented by the clinical, developmental, social, behavioural and educational data provided by individual affected member families. Each one is written in a family-friendly style but medically-verified by specialists and available for download from the website free of charge.

We also produce information guides on broader topics such as genetic testing and early intervention strategies ("After diagnosis: What happens next?"). We are honoured that Guy's and St Thomas' NHS Hospital Trust in London sends our 'Guide to Array CGH testing' to all its patients.

In 2010 over 90% of members responding to our survey agreed or strongly agreed that *"our helpline and information guides helped them better understand their child's rare chromosome disorder."*

We are working constantly on new information guides to cover the many new disorders being identified through more refined diagnosis. Our Information Officers in 2010/11 researched and published 12 more guides, taking us to 136 publications.

"I had checked your website months ago and at the time only saw information about 5q22. I was so thrilled when I checked again today and found that there is now so much written about 5q14.3." a parent

In 2011/12 we aim to produce 20 new information guides and a further 20 updates. We will also produce general interest guides such as 'holidaying with chromosome disorders and travel insurance', 'education' and 'equipment resources'.

Our website: www.rarechromo.org continues to act as a source of new members as well as a reference point for medical and other professionals. Members can access a discussion forum and the magazine archive. Last year, the website received over 500,000 visits suggesting that it is of value to many more people worldwide than just our own 8,000 members. 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. Unique also benefits from a Google Grant to channel traffic from Google searches to Unique's website, helping to ensure that parents reach Unique. Many searches through Google for information on specific chromosome disorders will give Unique as the first search result listed.

In 2010/11 we started the process of redesigning the website to make navigation easier. In 2011/12 that redesign will go live.

The Unique members' magazine: filled with families' personal stories and photographs, the magazine allows families to share their knowledge and experiences with other members and professional readers. It also provides members with helpful information on services to which they may be entitled (medical, educational, social, and financial) alongside advice on how to obtain them and other practical suggestions such as useful equipment or organisations to help with everyday living.

In 2010/11 we published two instead of our usual three editions of the magazine. The magazine is members' ongoing source of information but its high production and postage cost meant that the Trustees felt it was prudent to make a one-off cut to this service when funding looked uncertain in early 2011.

Over 3,500 member families receive the magazine by email now (up from 3,000 last year), saving us postage and printing costs and improving our carbon footprint. The printed copy reaches over 3,800 families including many members who do not have internet access.

In 2011/12 we will return to publishing three editions but will aim to reduce the size and print specification of the Magazine, to reduce costs in the longer term.

2. Practical Support to Families

Families contact us after the shock of an often frightening-sounding diagnosis with an uncertain prognosis. Facing the unfamiliar prospect of lifelong disability or life-threatening medical conditions with inexact information about severity, often a family's first step towards understanding and acceptance will be contact with Unique and its publications. By speaking to someone who understands what they are facing, parents feel less isolated.

Listening Ear Support Service: The initial point of contact for all new families is the Listening Ear telephone, postal and email helpline service. We send families a Welcome Pack containing our famous Little Yellow Book which explains chromosome disorders and what they may mean for a child's future in layman's language. But newly diagnosed families may have a myriad of more detailed questions which often only Unique has the expert information and knowledge to answer. With two geneticists in the Unique team, callers are assured of reliable information. The team draws on the medical histories of over 10,000 members covering thousands of rare chromosome disorders to provide information on the characteristics and impact of different disorders.

"Thank you so much for your time yesterday, it did mean an awful lot to have a caring and informed voice on the end of the phone in these particularly difficult times." a new parent

In 2010/11 we received over 13,200 telephone and email enquiries. The increase in new members means that calls, letters and emails to our Listening Ear Service are increasing fast. Considerable new investment will be needed in order to continue to provide this service to an expanding audience.

In 2010 we surveyed all the UK regional genetics centres to gain a better understanding of what kind of genetic testing is available in order to better inform members. In particular we are monitoring the implementation of more detailed Array CGH tests which are replacing the less sophisticated karyotyping performed over the last 40 years. We are able to inform members about the availability of more sophisticated testing that is limited in some genetics centres by NHS funding constraints.

Family Matching Service: In addition to the support of our staff, newly-diagnosed families particularly value the Family Matching Service that puts them in contact with members who share similar chromosome disorders as well as local families with other chromosome disorders. Lifetime support and friendship grow through such contacts.

Our 2010 members' survey found that over 90% of those responding 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."*

In 2011/12, to meet the growing demand, we intend to expand the capacity of the Listening Ear and Family Matching services by employing two new part-time members of staff.

3. A network for professionals and families

Professional awareness: Awareness-raising amongst professionals helps our members indirectly. We ensure that the professionals they encounter are informed about chromosome disorders and the challenges families face. In a survey of our members in 2010, 65% of respondents agreed or strongly agreed "information from Unique has helped their GP/Paediatrician understand their child's condition."

In 2010/11 our staff shared their knowledge on the challenges faced by our families and our work in supporting them with:

- the UK Genetic Testing Network's NHS commissioning conference on Array CGH at the Royal College of Pathologists
- Guy's Hospital, London on "Patient Perspectives on Array Testing"
- 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, genetics centres in Belfast and Dublin
- medical students at University College London on the challenges of living with a rare chromosome disorder in the family
- professional committees and advisory panels as expert patient representative, 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
- the British Society of Human Genetics and of the Association of Genetic Nurses and Counsellors' annual conferences
- World Rare Diseases Day and lobbying government through Rare Disease UK/Genetic Alliance UK.
- the American College of Medical Geneticists and the National Society of Genetic Counsellors annual conferences in North America, in conjunction with ISCA

In 2010/11, we were also involved in medical research projects such as:

- an application by Cambridge University and others for funding from the Medical Research Council for research into adults and ageing in genetically determined neuro-developmental syndromes.
- research at Oxford University into the developmental difficulties faced by some children with an extra sex chromosome.
- the advisory board for the Predictive Genetic Testing of Children (PreGenToC) project, funded by the BUPA Foundation and led by researchers from the Universities of Southampton, Newcastle, Manchester and Cardiff exploring the views of parents, young people, health care professionals and patient representatives about genetic testing during childhood when there are no immediate medical benefits.
- a research project at Southampton University into the Limits of Confidentiality in Genetic testing.
- the advisory board for the Wellcome Trust Sanger Institute's Decipher project and the scientific advisory board of the Sanger's Deciphering Developmental Delay (DDD) project in conjunction with the 23 regional genetics centres in the UK.

One of our objectives is to encourage greater research into chromosome disorders by assisting institutions in matching families to their projects. In 2011/12 we are helping to set up a project to study potential behavioural traits in 22q13 deletions (Phelan-McDermid Syndrome).

Public awareness: Unique seeks to educate the general public with education about chromosome disorders through the national and local press, TV and radio and social networking. In 2010/11 Unique was again one of Jeans for Genes' guest charities, raising awareness through a nationally recognised campaign for genetic disorders. A number of our families also featured in the media, describing their personal stories.

International networking: We are established in the UK but our membership spans 79 countries. This global spread is essential as the rarity of some of our families' chromosome disorders means that we may only find similarly affected people on the other side of the world. The quality of our database and publications, and likewise the quality of information given to our families, depends on collating data from the greatest number of families worldwide which itself depends on Unique being known to families and professionals worldwide.

A British doctor speaking at our 4q deletion Study Day this year underlined the issue:

"There are limitations to our work: one is the sample size. If I could have one third of the patients diagnosed in the US in the past year [to study] I would have great confidence in assigning the genes responsible for the clinical phenotype much better. So we definitely need increased sample size. A lot of things that are currently speculation would then be more real."

We have published translations of 43 guides into major European and world languages. Eight further translations are in preparation. Languages include Arabic, Danish, Dutch, French, German, Greek, Italian, Romanian and Spanish. These foreign-language publications help us develop strong working partnerships with other European and American clinical geneticists and support charities, extending the 'pool' of families known to be affected by chromosome disorders.

In 2010/11 Unique continued to play an active role in the UK and worldwide genetics and wider health community, setting up with similar charities in France and Germany a European rare chromosome disorder network, "Eurochromnet", as a registered French charity in order to apply for pan-European funding for Unique and its European partners. Unique staff participated in the Eurordis (European Organisation for Rare Disorders) and the European Society of Human Genetics (ESHG) conferences in 2010 and was congratulated for having one of the best information posters on its disorders among delegates at Eurordis.

We are also involved in discussions in the US about the creation of an international patient registry with ISCA (International Standards for Cytogenomic Arrays Consortium). We 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).

Families: Unique is listed on public information databases and the charity has established strong relationships with organisations such as Contact a Family and Genetic Alliance UK. They refer families affected by chromosome disorders to Unique.

Unique Local Contacts: Unique has a network of volunteer members who act as 'Local Contacts' in the UK and 24 countries worldwide. They support families of newly diagnosed children and signpost them to local services and other resources. As at the end of this year, March 2011, we had 156 local contacts, as well as many more volunteers engaged in fundraising and awareness-raising events. In 2011/12 we will be developing direct and regular communication between the Chair of Unique and our members in order to build links and encourage support with fundraising and awareness-raising by volunteers.

This year we launched a pilot local support group in Bristol and the South West to bring together local members, particularly isolated families or those who need face-to-face contact. Eighteen families were involved and they met up twice over the summer 2010, once for a sponsored walk and then for a family social event. This concept will be rolled out throughout the UK if we are able to secure funding.

Social Networking: Increasingly, new members find Unique through searching social networking sites such as Facebook rather than through websites and then continue to exchange information and support each other through Facebook. Our staff moderate and input into discussions on our Facebook page and "Facebook Café" discussion forum to ensure that users get an answer to their more challenging questions and to ensure accuracy in the information being exchanged. Facebook is now vital to maintaining the support of existing members and the wider Unique community of friends and families, as well as to drawing in new families.

By March 2011 we had 5,200 'fans' on our Facebook page, a number which is rising rapidly. Unique now has a presence on Twitter and Big Tent, other means of communication, networking and awareness-raising which we expect to grow substantially in the coming years. We keep increasing numbers of members and non-members in touch with fundraising activities and other Unique news through regular e-newsletters, a highly cost-effective way to maintain and increase Unique's profile.

Family Conferences and Study Days: Conferences and Study Days bring together families and professionals to develop understanding of specific disorders and stimulate informal support.

At our weekend residential conferences, members attend with their children in order to meet, share experiences and hear presentations from medical, developmental and behavioural professionals. This year Unique was delighted to secure finance from Jeans for Genes to fund our first conference in 3 years, to take place in spring 2012.

As part of our commitment to the support of high quality medical research, Unique holds chromosome-specific study days and weekends when families meet clinicians and researchers to exchange information about their particular syndrome and relevant research projects. We also arrange presentations of resources for children with special needs, such as equipment, from other helpful organisations.

In 2010/11 we held five study weekends for families affected by 4q deletions, 9q34.3 deletions, 8p23 deletions, 2q37 deletions and Pallister Killian Syndrome. Parents report that the weekends are excellent and that they come across much useful information. Families greatly appreciate the opportunity to meet others affected by the same disorder.

"Without families like you participating in studies like this, it's impossible to get any conclusions. So I really appreciate all the families participating in the study and the physicians with their detailed clinical phenotype. Hopefully we can find treatment for at least some aspects of the condition." a clinical geneticist

The study events provide excellent training and educational opportunities for young laboratory-based geneticists, as well as being a stimulus to ongoing research and the creation of web-based, disorder-specific sub-groups.

Financial Review

Income
Unique's stated income for 2010/11 is £265,614 against £268,799 in 2009/10 due to a reassessment of how we calculate donated services (see below). Our actual income increased in 2010/11 by around £20,000.

Our unrestricted income in 2010/11 from various trusts and from donations and fundraising by members, their friends, family and employers totalled £225,136. From charitable trusts and foundations we received unrestricted funding of £156,699 which mainly covers core running costs and restricted income of £40,478 which covers the cost of our Family Support Services, publications and study days.

We thank all our donors for their support.

Expenditure
Expenditure decreased slightly to £249,332 in 2010/11 (from £255,626 in 2009/10) due to a substantial saving of expense in online giving subscription charges, thanks to staff encouraging members to raise funds through Virginmoneygiving's more cost-effective sponsorship management system.

The ascribed value of **donated services** from professionals and volunteers (£26,929 in 2010/11 against £50,324 in 2009/10) dropped substantially, not because of an actual decrease in pro bono help from professionals and others but as a result of a reassessment of accounting rules for the treatment of donations in kind.

The Trustees wish to record their thanks to all these generous supporters and in particular to:
- The expert medical professionals around the world who verify and translate our publications
- Gemma Mitchell, for organising the sale of Christmas cards
- Trevor Searle, for his expertise and time spent on the database, website redesign, and new ICT
- Patrick Griffin, for his expertise and time spent supporting staff with their ICT
- Professor Maj Hulten, for checking and verifying Unique's chromosome disorder guides
- Red C PR agency, Manchester, for their advice on branding and PR.
- SupaStorage, Wimbledon, for the donation of storage space
- Carey Hunt, for her graphic design of Unique publications
- Farrer & Co Solicitors in Lincoln's Inn for use of their meeting rooms
- Our local contacts, other group members, their families, friends and work colleagues and all those who volunteer their free time and energy to raise funds for the group.

Cost of generating funds
Unique's main costs associated with fundraising were: the part-time fundraiser's costs at £7,860; marathon and race bonds (£3,642); merchandise costs at £2,475 (Christmas card printing, banners, t-shirts used at fundraising events); online giving costs (Virgin Money and JustGiving) £2,237.

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 (£ 139,011 at 31 March 2011) and tangible assets of £2,157 (hardware and a Tracey Emin print valued at £700).

The Charity's policy is 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 meeting, to ensure optimal returns. During the year we operated two Fixed Term Deposit accounts, with Birmingham Midshires and Bank of Ireland.

Activities to generate income
Revenue from the sale of Christmas cards continues to grow.

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

Reserves Policy
In 2010/11, the charity's policy was to hold reserves equivalent to two months' operating costs plus the cost of winding up the Charity. At 31 March 2011, unrestricted general funds of £111,046 were held.

In 2011, the Trustees reviewed this policy and decided in future to hold a sum equivalent to four months' average actual core operating costs for the previous year (not including the value of donations in kind). At this level, the Trustees feel that they would be able to continue to provide its core services. This policy will be reviewed regularly throughout the year. The Trustees have budgeted for reserves of £75,000 for the year 2011-12.

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 chromosome disorder irrespective of background, race, religion or culture. We are an equal opportunity employer.

Staff work from home and use teleconferencing and VOIP to minimise costs and carbon footprint.

Management of risk
The major risks to which the charity could be exposed, as identified by Trustees and senior staff, are considered and recorded in a risk register, most recently updated in June 2011, with contingency plans in place as operating conditions and/or performance change. The charity's position is kept under review and discussed in detail at each meeting of the Trustees as well as at other times.

Compliance and training
Given the importance to our work of personal and sensitive medical data, staff and Trustees are aware of the requirements of data protection law and received data protection training this year, as well as bereavement counselling training. All staff and Trustees are CRB checked.

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

Governance
The board of trustee-directors of the charity met regularly throughout the year with the senior management team to define strategy and monitor performance face to face, by conference call and by email.

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.

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

Trustees' summary
Our Finance Officer produces detailed monthly management accounts which are reviewed and discussed monthly by Trustees and senior staff. Unique carries out a robust financial review before each Trustees' Meeting when the annual budget is re-forecast in the light of up-to-date information to ensure that any potential problems are identified early and prudent action taken.

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 chromosome disorder.

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

The Trustees who served during the year are detailed on page 1 of this report. Trustees serving at 31 March 2011 are:

Edna Knight MBE- Life President and trustee
Founded the charity in 1984 as the Trisomy 9 Support Group after the birth of two daughters with chromosome disorders. The charity expanded to include families affected by any rare chromosome disorder. With her 27 years helping families affected by chromosome disorders, she is an inspiration and a beacon to our Trustees and staff. Edna is Unique's local contact for Middlesex.

Sophie Sainty – Chairman (from January 2011) and trustee
Parent of a 9 year old with a chromosome disorder and appointed a Trustee in December 2009. Former solicitor in commercial and regulatory law, she has previous experience as a Trustee and Company Secretary in the charitable sector. She is a Chair of Governors at a community school and is Unique's local contact for Hammersmith, Fulham and Chiswick.

Gillian Manvell – Trustee, former Acting Chairman/Chairman (2005-2011)
Parent of a young adult with a chromosome disorder and a Trustee for over 18 years. With a business background, she runs an educational technology company and in addition, has held a wide variety of voluntary offices since the birth of her children. Gill is Unique's local contact for South London.

Sally Cohen – Trustee
Partner of the Long Run Venture and former Managing Director of Elizabeth Arden UK/Ireland, with 25 years of marketing experience in large brand companies; joined Unique as a Trustee this year having worked previously with Unique on strategy as a Pilotlight mentor.

Employees:

Beverly Searle - Chief Executive Officer
Post-doctoral microbial geneticist and mother of an adult with a chromosome disorder. Provides frontline specialist services to member families and professionals, and awareness-raising of chromosome disorders among professionals, fundraisers and policy makers.

Craig Mitchell - Operations Manager and Company Secretary
Former operations manager at a media and telecoms business and a parent of a child with a chromosome disorder. Responsible for the day-to-day operational management of the charity and fundraising.

Marion Mitchell - Family Support Officer
Customer services background and the mother of a teenager with a chromosome disorder. Day-to-day point of contact for family support. She sends out our Welcome Pack, manages online discussion groups and sources content for the magazine.

Prisca Middlemiss - Senior Information Officer
Medical journalist who lost a son to a chromosome disorder. Directs the research and production of the chromosome disorder guides, organises syndrome-specific events and liaises with medical professionals in the UK and abroad.

Sarah Wynn - Information Officer
Married to a balanced chromosome translocation carrier and suffered miscarriages due to chromosome disorders; their oldest child is also a carrier. Formerly a post-doctoral geneticist, researches and compiles our chromosome disorder guides and genetic testing.

Julie Griffin - Finance & Fundraising Executive Officer (until 14 Feb 2011) and volunteer Finance Officer at financial year end. Former marketing manager in banking who lost a child to a chromosome disorder. Produces our management and company accounts, overseeing the day-to-day financial controls and members' fundraising activities.

Sarah Clifton - Fundraising (Consultant)
Professional healthcare fundraiser and previously Head of Fundraising at Action for ME. Part-time consultant to Unique on trusts and major donors.

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 14 October 2011 and signed on their behalf by

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

Independent Auditors' Report

To The Members of

Rare Chromosome Disorder Support Group

We have audited the financial statements of the Rare Chromosome Disorder Support Group for the year ended 31 March 2011 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.

Independent Auditors' Report

To The Members of

Rare Chromosome Disorder Support Group

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.

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 2011 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.

Date:

Alison Godfrey 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 2011

	Note	Restricted £	Unrestricted £	**2011 Total £**	2010 Total £
Incoming Resources					
Incoming Resources from Generated Funds:					
Voluntary Income	2	-	156,699	**156,699**	141,326
Activities For Generating Funds	3	-	67,838	**67,838**	71,147
Investment Income		-	599	**599**	2,403
Incoming Resources from Charitable Activities:	4				
Family Support Services		9,300	-	**9,300**	15,925
Information Services		31,178	-	**31,178**	37,998
Total Incoming Resources		40,478	225,136	**265,614**	268,799
Resources Expended					
Costs of Generating Funds:					
Fundraising Costs		59	32,159	**32,218**	43,120
Merchandise Costs		-	2,931	**2,931**	3,854
Charitable Activities:					
Family Support Services		10,103	80,400	**90,503**	96,181
Information Services		55,510	51,659	**107,169**	94,326
Governance Costs		-	16,511	**16,511**	18,145
Total Resources Expended	5	65,672	183,660	**249,332**	255,626
Net Incoming Resources Before Gains & Transfers		(25,194)	41,476	**16,282**	13,173
Transfers Between Funds		-	-	**-**	-
Net Movement in Funds	6	(25,194)	41,476	**16,282**	13,173
Reconciliation of Funds					
Total Funds Brought Forward		25,890	109,570	**135,460**	122,287
Total Funds Carried Forward		696	151,046	**151,742**	135,460

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 2011

	Note	£	2011 £	2010 £
Fixed Assets				
Tangible Fixed Assets	9		**2,157**	3,402
Investments	10		**700**	700
			2,857	4,102
Current Assets				
Stock	11	**305**		340
Debtors	12	**16,508**		8,067
Cash at Bank and in Hand		**139,011**		129,894
		155,824		138,301
Creditors: Amounts Due Within 1 Year	13	**6,939**		6,943
Net Current Assets			**148,885**	131,358
Net Assets	14		**151,742**	135,460
Funds	15			
Restricted Funds			**696**	25,890
Unrestricted Funds:				
Designated Funds			**40,000**	42,537
General Funds			**111,046**	67,033
Total Funds			**151,742**	135,460

Approved by the trustees on 14 October 2011 and signed on their behalf by

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

Rare Chromosome Disorder Support Group

Notes to The Financial Statements

For The Year Ended 31 March 2011

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 £	**2011 Total £**	2010 Total £
Grants > £1,000				
Garfield Weston Foundation	-	25,000	**25,000**	-
The John Ellerman Foundation	-	25,000	**25,000**	-
Sylvia Adams Charitable Trust	-	10,000	**10,000**	-
Jeans 4 Genes	-	2,500	**2,500**	-
Bothwell Charitable Trust	-	2,000	**2,000**	-
Glaxo Smith Kline	-		**-**	25,000
The Grocers' Charity	-		**-**	9,428
Hugh Fraser Foundation	-		**-**	3,000
Smith & Williamson	-		**-**	2,000
Health Foundation	-		**-**	-
Grants < £1,000	-	7,750	**7,750**	4,900
Donated Goods / Services *	-	26,929	**26,929**	50,324
General Donations	-	32,333	**32,333**	22,155
Corporate Donations	-	5,385	**5,385**	5,917
Gift Aid	-	13,098	**13,098**	13,328
Give As You Earn	-	667	**667**	1,296
Overseas Donations	-	5,410	**5,410**	3,373
Pyramids	-	460	**460**	605
Miscellaneous Income	-	167	**167**	-
Total Voluntary Income	-	156,699	**156,699**	141,326

* Donated services consist of the following:	**2011 Total £**	2010 Total £
Google AdWords (free web advertising)	**9,308**	10,559
Website & database design, development & maintenance	**2,800**	4,970
Professional verification of information in the charity's publications	**12,480**	20,800
Translation of charity's publications	**-**	2,675
Professional services	**-**	1,200
Secretarial services	**-**	320
IT support	**1,050**	9,800
Storage Facilities	**1,291**	-
Total Donated Services	**26,929**	50,324

3. Activities For Generating Funds

	Restricted £	Unrestricted £	**2011 Total £**	2010 Total £
Fundraising Activities	-	64,260	**64,260**	66,648
Christmas Card & Merchandise Sales	-	3,578	**3,578**	4,499
Total Activities For Generating Funds	-	67,838	**67,838**	71,147

4. Incoming Resources From Charitable Activities

	Restricted £	Unrestricted £	**2011 Total £**	2010 Total £
Family Support Services:				
Grants				
29 May 1961 Charitable Trust	5,000	-	**5,000**	5,000
The Gibbons Family Trust	3,000	-	**3,000**	-
The Alchemy Foundation	500	-	**500**	-
Reuben Foundation	250	-	**250**	-
Denman Charitable Trust	250	-	**250**	
VICTA		-	**-**	6,125
Felicity Wilde	-	-	**-**	3,000
Dorothy Pamela Smith Trust	-	-	**-**	800
Lynn Foundation	-	-	**-**	500
B-CH 1961 Charitable Trust	-	-	**-**	500
Donations	300	-	**-**	-
Information Services:				
Grants				
Baily Thomas Charitable Trust	15,000	-	**15,000**	-
Jeans 4 Genes	6,428	-	**6,428**	5,000
The Childwick Trust	5,000	-	**5,000**	-
Goldsmiths Company Charity	2,000	-	**2,000**	-
The London Law Trust	1,000	-	**1,000**	-
The Albert Hunt Trust	1,000	-	**1,000**	-
The Jules Thorn Charitable Trust	750	-	**750**	-
The Grocers' Charity	-	-	**-**	25,572
K U Leuven R&D - Eurogentest Project	-	-	**-**	3,072
The Kathleen Laurence Trust	-	-	**-**	1,000
R S Brownless Charitable Trust	-	-	**-**	150
Donations	-	-	**-**	3,204
Total Charitable Activities	40,478	-	**40,178**	53,923

5. Total Resources Expended

		Fundraising Costs £	Merchandise Costs £	Family Support Services £	Information Services £	Governance Costs £	Support Costs £	**2011 Total £**	2010 Total £
Staff Costs (Note 7)		17,716	-	55,154	54,935	6,991	-	**134,796**	134,726
Training		-	-	-	-	342	-	**342**	306
Postage & Distribution		1,282	629	9,366	593	15	-	**11,885**	17,034
Printing & Design		480	2,166	6,461	2,068	238	-	**11,413**	17,848
Stationery		563	84	1,822	1,242	198	-	**3,909**	4,023
Subscriptions, Licences & Charges		10,623	-	163	1,093	388	221	**12,488**	14,492
Travel & Subsistence		339	46	464	4,759	1,110	-	**6,718**	4,448
Room Hire & Event Costs		-	-	-	24,317	101	-	**24,418**	1,140
Equipment & Software		72	-	542	78	-	-	**692**	1,844
Books & Publications		-	-	-	78	-	-	**78**	75
Home Office Costs		560	-	1,632	1,006	275	125	**3,598**	3,600
Website & Database Development	*	-	-	423	2,800	-	-	**3,223**	5,413
Advertising	*	-	-	9,308	-	-	-	**9,308**	10,559
Insurance		-	-	-	552	2,325	-	**2,877**	2,924
Audit & Accountancy		-	-	-	-	2,878	-	**2,878**	2,903
Consultancy	*	-	-	4,000	12,480	1,650	-	**18,130**	33,275
Depreciation		-	-	-	-	-	1,245	**1,245**	1,046
Storage Expenses	*	-	-	-	-	-	1,291	**1,291**	-
Profit on Disposal of Fixed Assets		-	-	-	-	-	-	**-**	(38)
Miscellaneous Costs		-	6	-	-	-	37	**43**	8
Sub-Total		31,635	2,931	89,335	106,001	16,511	2,919	**249,332**	255,626
Allocation of Support Costs		583	-	1,168	1,168	-	(2,919)	-	-
Total Resources Expended		**32,218**	**2,931**	**90,503**	**107,169**	**16,511**	**-**	**249,332**	255,626

Expenditure categories marked with * include donated services (see note 2).

6. Net Movement in Funds

This is stated after charging:

	2011	2010
	£	£
Depreciation	**1,245**	1,046
Trustees' indemnity insurance	**1,378**	1,378
Trustees' reimbursed expenses	**-**	-
Auditors' remuneration:		
▪ Statutory Audit	**2,760**	2,644
▪ Grant Audits	**-**	259

7. Staff Costs and Numbers

Staff costs were as follows:

	2011	2010
	£	£
Salaries and Wages	**116,074**	118,003
Social Security Costs	**10,862**	10,718
Freelance Staff	**7,860**	6,005
	134,796	134,726

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

	2011	2010
	No.	No.
Average number of employees (full-time equivalent)	**4.15**	4.37

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 2010	**7,472**
Additions in year	**-**
Disposals in year	**-**
At 31 March 2011	**7,472**
Depreciation	
At 1 April 2010	**4,070**
Charge for the year	**1,245**
Disposals in the year	**-**
At 31 March 2011	**5,315**
Net Book Value	
At 31 March 2011	**2,157**
At 31 March 2010	3,402

10. Investments

	2011	2010
	£	£
Artwork	**700**	700

A Tracey Emin was donated in 2005. The trustees have no immediate plans to sell the print consequently it has been reported as a fixed asset investment in the accounts. It is valued at the average of two professional valuations.

11. Stock

	2011	2010
	£	£
Merchandise	**305**	340

12. Debtors

	2011	2010
	£	£
Prepayments	**1,778**	4,839
Other Debtors	**14,730**	3,228
	16,508	8,067

13. Creditors : Amounts Due Within 1 Year

	2011	2010
	£	£
Accruals	**3,858**	3,905
Other Taxation & Social Security	**3,081**	3,038
	6,939	6,943

14. Analysis of Net Assets Between Funds

	Restricted Funds	Unrestricted Funds	**Total Funds**
	£	£	**£**
Tangible Fixed Assets	-	2,157	**2,157**
Investments	-	700	**700**
Current Assets	696	155,128	**155,824**
Current Liabilities	-	(6,939)	**(6,939)**
Net Assets at 31 March 2011	**696**	**151,046**	**151,742**

15. Movements in Funds

	At 1 April 2010 £	Incoming Resources £	Outgoing Resources £	Transfers Between Funds £	**At 31 March 2011 £**
Restricted Funds					
VICTA	686	-	(686)	-	**-**
Eurogentest Fund	3,209	-	(2,720)	-	**489**
Helpline	-	8,750	(8,750)	-	**-**
Information Project	-	24,750	(24,750)	-	**-**
Community Support	-	550	(550)	-	**-**
Dorothy Pamela Smith Trust	500	-	(293)	-	**207**
Study Days	21,495	6,428	(27,923)	-	**-**
Total Restricted Funds	25,890	40,478	(65,672)	-	**696**
Unrestricted Funds					
Designated Funds:					
Listening Ear Fund	42,537	-	-	(2,537)	**40,000**
Total Designated Funds	42,537	-	-	(2,537)	**40,000**
General Funds	67,033	225,136	(183,660)	2,537	**111,046**
Total Unrestricted Funds	109,570	225,136	(183,660)	-	**151,046**
Total Funds	135,460	265,614	(249,332)	-	**151,742**

Purposes of Restricted Funds

VICTA	To fund part of the Family Support Officer's salary
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.
Community Support	To fund family services

Purpose of Designated Fund

Listening Ear Fund	The trustees have decided to designate £40,000 from general funds to the charity's 'Listening Ear' project. This sum will ensure that the Unique helpline, a frontline service providing expert response to first-time callers from the UK and around the world, will be staffed appropriately for at least part of each UK working day during 2011-12.