
Annual Review

2010/2011



Genetic Alliance UK
Supporting. Campaigning. Uniting.



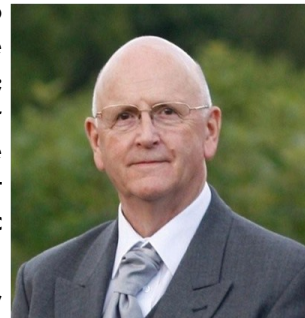
Chair's Introduction

The founders of Genetic Alliance UK did so to create a body that could provide relief and support for persons and families whose lives are affected by genetic conditions both rare and common. They also sought to advance the education of the public concerning genetic disorders. In essence it has developed into the 'national voice' for people, groups and families affected by genetic conditions.

In achieving these goals, Genetic Alliance UK undertakes selective projects funded by outside agencies. All of these are important to our membership and are specifically designed and carried out to provide ongoing benefits for them. In taking one of them as an example of how Genetic Alliance UK meets its goals; Rare Disease UK (RDUK) exemplifies our aims in that it seeks to influence government policy in all the UK countries to meet the needs of individuals and families affected by rare diseases without increasing the overall costs to their exchequers.

In addition to its specifically funded projects Genetic Alliance UK carries out functions that are not externally funded. The national and international influence of our Director, Alastair Kent, is extensive and we were proud to see that people outside our organisation recognise his role in improving services for genetic conditions by means of his OBE honour this year.

Other core functions are strategically important to Genetic Alliance UK's existence. These involve policy analysis and formulation; fundraising; parliamentary liaison and communication with our membership and the public. We will concentrate on ensuring that we can maintain a significant presence and influence on provision of genetic services in the UK for the benefit of our growing membership, now over 140 patient organisations, which work to benefit all those affected by genetic conditions.



Christopher.J.Friend

Treasurer's Report

There is no doubt that this has been a challenging year. The rebranding has provided us with a stronger positioning and image to further our campaigning and support on behalf of our membership. It was developed with help from our friends at Tudor Reilly who gave generously their time and expertise. However, the application of the changes did involve us in some £20,000 of necessary expenditure.

Our major campaign activity was the development of Rare Disease UK. This was in response to the Council of the European Union's Recommendation on action for rare diseases that was adopted by each Member State of the EU. We published our recommendations in the form of a report entitled "Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy". We hope that the recommendations will be considered carefully and that they will be as influential with the UK's governments and NHSs as our past work.

It is difficult to understate the importance of the potential change that a UK rare disease plan can bring to patients. As a result we committed substantial resources to this project, beyond the support funds that were raised. This, along with increased core activity costs, has consumed much of our reserves.

This has meant we have had to introduce cost savings and efficiencies that will extend into our 2011-12 financial year. Like most charities, finding funding is proving ever more challenging as the economy struggles for growth. However, our commitment to improving the treatment and experience of patients and their families remains our overriding ambition. We now have a significant management challenge to rebuild our reserves and improve our cost effectiveness.



Christopher Goard

What we do

Genetic Alliance UK is the national charity with a membership of over 140 patient organisations supporting all those affected by genetic conditions. We aim to improve the lives of people affected by genetic conditions by ensuring high quality services and information are available to all who need them.

Supporting: We raise awareness of genetic conditions and improve the quality of services and information available to patients and families.

Campaigning: We campaign on issues of policy and practice to influence governments, policy makers, industry and care providers, such as the National Health Service.

Uniting: We provide a united voice for all those affected by genetic conditions, enabling us to work together towards a common goal of making life better for patients and families at risk.

Rebranding

In June 2010, the Genetic Interest Group (GIG) rebranded as Genetic Alliance UK. The rebranding was motivated by the need to more clearly communicate what we do. To ensure that we had met our objectives, a survey was undertaken in late 2010 and an overwhelming majority of our members felt that the new name and branding of Genetic Alliance UK more clearly matched and communicated our aims and work.

As part of the rebranding we introduced new communications initiatives such as a Facebook page and an exciting and informative monthly e-newsletter.

Influencing Policy in the UK

The past year has been particularly busy for our policy team at Genetic Alliance UK. The proposed large scale reorganisation to the NHS in England has meant that championing patients' interests has, arguably, never been more important; particularly as the reforms are set against the background of budget cuts. We have used this opportunity to promote more efficient use of resources which will benefit patients and make better use of limited budgets.

The NHS England reorganisation

At Genetic Alliance UK we have been working hard to communicate the needs of patients and their families to ensure that these are fully considered and taken into account during the NHS reorganisation. As this reorganisation is the biggest since the NHS was founded, it presents an opportunity to improve health services and support for those affected by genetic conditions.

Genetic Alliance UK has consulted widely with its members to ensure that their voices are heard and has responded to every public consultation about the NHS reorganisation. This is something that many larger patient organisations did not manage to do. As one of over 6,000 organisations who responded to the various consultations, we were pleased when our response was quoted by the Government in their response.

We will continue to work hard on the reorganisation as the Health and Social Care Bill pushes through Parliament and changes are implemented

so that patients' views are properly represented and acted upon in the new NHS.

Working with Committees

During the past year Genetic Alliance UK has been an active member of many regulatory and advisory committees. We believe that by working with these committees we can influence policy makers. For example, Alastair Kent, our Director, remained on the Department of Health's Gene Therapy Advisory Committee (GTAC) which examines research proposals for gene and stem cell research work outside the Human Fertilisation and Embryology Authority's remit.

Policy work also helps to inform our projects. Our work with GTAC, for example, helped to inform the PatientPartner project (further details on page 15) which looked to offer advice to patients looking to get involved in clinical trials. The Asking Relevant Questions project (further details on page 16) also enabled us to develop a relationship with the Association of British Insurers (ABI) which we have used to continue to represent the interests of people with genetic conditions in discussions regarding the use of predictive test results for insurance.

Alastair Kent, is also a member of the Human Genetic Commission which advises the Department of Health on the impact of new developments in human genetics. It is important that we represent patients' views through committees such as this so that the Department of Health can truly evaluate the potential benefits of any new developments in human genetics to those affected by genetic conditions.

Policy consultations responded to included:

- Academy of Medical Sciences review of the regulation and governance of medical research.
- Department of Health consultations on the NHS reorganisation:
 - White Paper on the NHS reorganisation, 'Equity and excellence Liberating the NHS'.
 - Six more detailed consultations accompanying the White Paper, covering commissioning; outcome measures; democratic legitimacy in health; regulating healthcare providers; choice; and information.
- Other Department of Health consultations on: Public Health; Value-Based Pricing; the Cancer Drugs Fund; Refreshing the Carers' Strategy; Government response to the House of Lords Genomics Inquiry.
- European Commission consultations on: the review of the In-Vitro Diagnostics Directive; the review of the Clinical Trials Directive; the RTD Health Impact Survey.
- European Medicines Agency (EMA) consultations on: the Agency's Roadmap to 2015; the procedure for involvement of primary care organisations in safety communications.
- House of Commons Health Select Committee reviews on public spending and commissioning.
- Human Fertilisation and Embryology Authority (HFEA) Ethics Committee questionnaire.
- Law Commission consultation on adult social care.
- National Institute of Health and Clinical Excellence (NICE) consultation on the response to the Kennedy Review on services for young people;
- Nuffield Council consultation on organ donation.

Working beyond Westminster

As well as our work in England, our work in Scotland, Wales and Northern Ireland has been particularly successful.

In Scotland one of the central themes of our work has been to increase the level of patient engagement with government decisions on health care. To this end we expanded our Virtual Patient Panel, an online network of patient representatives who are willing to be contacted to share their views on health issues and policy changes in Scotland.

We also launched our Supporting Patient Groups project which assists in the creation of patient groups to support those with rare conditions who currently do not have a support group. We are pleased that we have established a Paroxysmal Nocturnal Haemoglobinuria support group (PNH). As well as this, our public affairs work surrounding the Rare Disease UK (RDUK) report (see page 11) has continued as we built strong relationships with officials and Members of the Scottish Parliament (MSPs) and our work on committees in Scotland, including the National Services Division Public Reference Group, continued.

In Wales the public affairs work around the RDUK report also involved meeting with prospective and successful Assembly Members (AMs) to ensure they were aware of the need for a rare disease plan and the report which RDUK had produced. There was great success with our familial hypercholesterolaemia (FH) project. There is now an all-Wales NHS service which aims to find and diagnose people at risk of this condition. The new service has appointed three cardiac nurses and three genetic

counsellors and is the first of its kind in the UK. Securing funding for this against the backdrop of NHS cuts is a significant achievement and we are delighted to have played a fundamental role in it.

Work in Northern Ireland has focused on building relationships at Stormont with a view to driving forward the rare disease plan. The RDUK “Improving Lives” report was launched at Stormont in March to a wide range of stakeholders including the Members of the Legislative Assembly (MLAs) and the Department of Health, Social Services and Public Safety.

“I would like to thank you as an individual and Genetic Alliance UK as an organisation, for your support and help in the development of the Wales FH Family Cascade service. Your input has been very important in making sure that we have kept our focus on the needs of patients and families.”

Email to Genetic Alliance UK’s Wales Development Officer, from Dr Ian McDowell, Chair of the Wales FH Cascade Service Steering

We have also played a fundamental role in establishing a Northern Ireland Rare Disease Partnership with a group of patient support organisations and the Northern Ireland Patient Client Council. We feel that these new relationships and alliances will help us to ensure that patients’ views are represented as effectively as possible.

Policy Campaigns in Europe

Animal Research

Genetic Alliance UK's long-running work regarding the regulation of animal research in the EU paid off in September 2010, when the European Parliament voted in favour of a compromise package to pass the revision of the directive governing research using laboratory animals. Initial drafts of the review would have severely limited biomedical research in the EU. As part of the European Genetic Alliances' Network, Genetic Alliance UK strategised with other stakeholders and coordinated the patient campaign in Europe. This included statements of consensus from the patient community and an event for Members of the European Parliament to allow them to understand the patient perspective. The new directive has now been finalised and will be transposed into UK law in 2011-12.

In Vitro Diagnostics and Clinical Trials

In addition to the campaign work in the European Parliament, we responded to two major consultations from the European Commission which will influence the planned review of the medical devices directive and the clinical trials directive. In vitro diagnostics, which include genetic tests, are regulated by the Medical Devices Directive.

Rare Disease

There is more information on our work on rare diseases in the UK on the next page; however we should remember that it stemmed from work on rare disease in Europe. This year we have been offering our advice and guidance regarding the formation of other rare disease organisations across Europe. We are pleased that Alastair Kent was invited to be a member of the EU Committee of Experts on Rare Diseases, which will advise the European Commission.

Rare Disease UK

Rare Disease UK (RDUK) has been a particular success story over the past year. Membership has more than doubled from 350 to well over 800 organisations and significant milestones have been reached in terms of the publication of two reports, the hosting of four Rare Disease Day receptions and the hosting of a successful Europlan (European Project for Rare Diseases National Plans Development) conference in November 2010.

"I've just been reading through the Rare Disease UK report that you launched at Rare Disease Day. It's a gold mine of information." Email to Rare Disease UK from Nick Sireau, Chairman, AKU Society



Alastair Kent presenting the report to Health Minister Earl Howe at the Westminster parliamentary reception.

The report "Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy", was launched at Rare Disease Day receptions across the UK in February 2011. The receptions were held at Westminster, Holyrood, Stormont and Cardiff Bay and were attended by patient group representatives, patients and their families, researchers, academics, representatives from industry and health-care professionals.



RARE DISEASE | UK

The National Alliance for people with rare diseases & all who support them

The report is the most comprehensive and wide-ranging review of services for patients with rare diseases ever undertaken in the UK. In order to inform the report, focus groups were held in each home nation to gather as much feedback from patients, clinicians, patient groups and other interested parties.

The report aims to influence the plan for rare diseases which the UK's governments are committed to developing and implementing by 2013. We are looking forward to all future consultations on the plan.

As well as the extensive work undertaken to inform the strategy document, RDUK produced a report entitled "Experiences of Rare Diseases: An Insight from Patients and Families." The report was based on the largest ever



Attendees at the Scottish parliamentary reception where the "Improving Lives" report was launched.

UK survey of rare disease patients and their families, with responses from 600 patients and families affected by over 100 rare conditions. We will use the findings from this study to promote better awareness of rare diseases amongst all stakeholders.

"I want to thank you so much for everything that went to make the Westminster Rare Diseases Event such a resounding success. It was such an important opportunity to raise the profile of the needs of so many people with rare conditions. Also it was good to be able to speak to members of parliament and others who have our interests at heart. At this time of Health Service Reforms it is especially important that we have a strong voice in the planning of services for orphan conditions." **Email to Rare Disease UK from Ann Price, HAE-UK**

In November 2010, RDUK hosted the UK Europlan conference. This was one of 15 conferences held around Europe to promote joint knowledge-sharing between Member States as they develop and implement rare disease plans or strategies. The event provided a great opportunity to develop the UK rare disease plan and also to provide our insight into other plans which are being put together across Europe.

Rare Disease Day 2011

Rare Disease Day was bigger than ever this year with events being held in 40 countries around the world. RDUK hosted four events which were held in each of the four home nations' parliaments. These were well attended and received a very positive response.



Attendees representing the Haemophilia Society with Jeff Cuthbert AM at the Welsh Assembly reception. Many other delegates also got to meet their representatives at the events.

The theme for this year was 'Rare but Equal' and emphasised the right for rare disease patients to have equitable access to diagnosis, services, information and support as those affected by more common conditions.

Projects

This year the projects that Genetic Alliance UK have undertaken achieved impressive results that will help to make a difference to patients and families affected by, or at risk of, genetic disorders.

Past projects

PatientPartner

PatientPartner set out to promote the role of patient organisations in the clinical trials context. Underpinning this aim was the belief that better relations between patients and clinical researchers will lead to more patient focused trials which more closely match patients' needs.



This project produced two guides which will facilitate clear dialogue between all parties and stakeholders. One was aimed at sponsors and investigators of clinical studies and the second was aimed at patients and patient groups. Over 350 guides have been distributed to key stakeholders around Europe so far. These will lead to a better relationship between patients and clinical researchers.

Asking Relevant Questions

The aim of this project was to improve the interaction between insurance companies and applicants with complex medical conditions. Through the enquiries we receive at Genetic Alliance UK we know that some patients are confused by insurance policies and what they need to declare to companies when applying for cover.

We made a number of recommendations from our work with patients, to make the application process for insurance policies much easier. The report was distributed to insurance companies in the expectation that it will lead to an easier and quicker application process for patients affected by genetic conditions.

Although the results of this project may take a while to filter through the industry, we are encouraged by the relationships we have developed with some insurance companies and the Association of British Insurers (ABI).

NanoMed Round Table

The NanoMed Round Table's main purpose was to provide European stakeholders with a set of recommendations to support decision making regarding medical innovations.

Genetic Alliance UK led the Patients' Needs Working Group and represented patients' interests on the steering group. We found that

nanomedicine is viewed as a promising and positive technology, although often the levels of awareness and knowledge were low.

The final report was launched at the European Parliament and distributed to policy makers at a European level and to respective national policy makers. It will help to create an environment which is supportive to the research and development of nanomedicine.

Continuing Projects

Ethnicity and Access

This project aims to discover why there is under-representation from minority ethnic groups in referrals to cancer clinical genetics services in England. The project will also look at developing methods to address this inequity in cancer services.



Interviews have been conducted with a number of clinicians, patients and representatives of the three minority ethnic communities on which the research is focused: South Asian, Black Caribbean and White Irish. The project is being undertaken in partnership with the Division of Primary Care at the University of Nottingham and has already identified issues with the cancer referral process which will help inform the final recommendations of the study.

Facilitating Networks

The Facilitating Networks Project addresses the difficulties that children, adults and families with rare genetic disorders experience in receiving good information and optimal healthcare for their disease. This has been achieved through the development of networks of expertise for groups of rare genetic conditions.

The nine patient groups participating in this project have formed five networks for the following conditions: Ataxia; Cerebral Cavernous Malformations; Hypermelanosis of Ito; Rasopathies; Familial Adenomatous Polyposis.

In partnership with specialist clinicians each network has undertaken work in key areas of health and social care that will begin to improve the quality of services made available to patients and families who require them.



An Ataxia study day hosted by the Facilitating Networks project. The project has hosted many of these for various conditions. Each one is attended by clinicians and healthcare professionals from across the UK

quality of services made available to patients and families who require them.

The project successfully launched the Rasopathies network with a prestigious House of Lords reception in September 2010. This event gave the network's constituent groups an opportunity to come together and raise the profile of this initiative amongst medical professionals from within and outside

of the UK. Opportunities to educate Healthcare professionals have been created by coordinating medical study days specific to the conditions within each network. These events have been hugely successful with many delegates affirming their intentions to use the information obtained to inform their future clinical practice.

As this project moves into its final stages, the facilitating networks project is proud to have played an instrumental role in developing networks that will continue to be of benefit to individuals and families affected by these rare genetic conditions for some years to come.

RAPID

Reliable Accurate Prenatal non-Invasive Diagnosis (RAPID) is a UK-wide project which will improve the quality of NHS prenatal diagnosis services. The involvement of Genetic Alliance UK in the project will ensure that patients' views and needs are taken into account fully before the new technology is brought into routine clinical practice.

Over the past year Genetic Alliance UK has interviewed women and their partners who have used non-invasive prenatal diagnostic testing to determine the sex of the fetus. Initial findings suggest that this procedure can help to inform antenatal care and delivery, create peace of mind or ensure that the need for further, more invasive testing is focused on those women who seem to be at the highest risk.

Variations across different conditions have also been identified and we look forward to seeing how these develop through further interviews. Over the coming year we will also look to develop and pilot information materials for service users.

New Projects

The past year has been particularly productive for us at Genetic Alliance UK. We have started four exciting projects with another one beginning in May 2011.

Route Maps for Rare Conditions

This project will build upon the success of the 2007 Family Route Map project by improving information, access to and coordination of care for people affected by rare genetic conditions. This will be presented in a practical and cost-effective framework to ensure that both patients and

patient groups can easily access and use the route maps to get access to the services they need.



We were delighted by the enthusiastic response of patient groups wanting to be a part of the project and decided to increase the number of groups involved in the project from eight to ten.

“The Jennifer Trust for Spinal Muscular Atrophy (JTSMA) is delighted to be working with Genetic Alliance UK as one of the charities involved in the Route Maps for Rare Conditions Project.

The opportunity to take part in this project and develop our own route map with the support of a project manager and the other nine groups is enabling us to develop a very important piece of work.

This will have huge benefits for children and adults living with a diagnosis of SMA, and for the health care professionals supporting them.”

Heather Brown, General Manager, The Jennifer Trust for Spinal Muscular Atrophy

Already three draft route maps have been produced and are currently being reviewed. A toolkit is also being developed to enable other groups, not immediately involved with the project, to develop their own route maps to benefit patients in the future.

Risks and Benefits

This project is a collaboration with the Welsh Institute for Health and Social Care (WIHSC) at the University of Glamorgan. It will examine how patients and their families perceive the balance between the risks and benefits of new biomedical therapies.

Based on a citizens' jury model, 16 patients and family members will debate and dissect the issues together. The project has started well and is currently recruiting the jury after an overwhelming response from patients to take part. The first meeting of the jury takes place in September 2011.



EuroGentest II

This project will be looking to build on the achievements of the first EuroGentest project. It will focus on increasing the reach and penetration of the patient information leaflets developed over the past five years. This will be done by ensuring all the online materials are kept up to date and translating all of the materials in to new languages to add to the 28 languages already featured in the resources.

Paving the Way

The aim of this project is to promote the self-management of conditions by patients and to offer advice to patients and healthcare professionals who want to embrace this empowering approach. To this end, videos of interviews with patients and health professionals who have experience of self-management of their conditions will be recorded and made freely available on both our website and YouTube. They will also be distributed to healthcare professionals and patient networks.

This resource will provide another long term source of information to help patients.

SWAN – Supporting Families with Children with Undiagnosed Conditions



Syndromes Without A Name (SWAN UK) will address issues raised on research Genetic Alliance UK undertook during the summer of 2010 which found that undiagnosed families experience difficulties in accessing help and support from various services including health, educational and social services. In order to address this gap in services we secured funding from the Big Lottery Fund to develop a hub for information and support between families of children with undiagnosed conditions.

Funding was granted in January 2011 for five years and the project begins in May 2011.

The Year Ahead

The next year will see increasing demand on us as we work on a growing range of issues. Following the launch of their landmark report for rare diseases in February, RDUK will continue to work with decision makers from health departments across the four home nations to maintain a dialogue while the plan for rare diseases is being drawn up. A public consultation on the plan is being produced and we will respond in detail when it is made public.

Along with the rare disease plan, the reorganisation of the NHS in England presents an unprecedented opportunity to improve treatment and support for people with genetic conditions. We will look to respond to every consultation where there is an opportunity to improve the level of care, information and support available to patients affected by genetic conditions.

As part of our ongoing policy and strategic advocacy work, we will continue to have an active presence and voice on a wide range of committees at both a national and international level.

The Scottish Government has agreed to extend the funding through the Children, Young People and Families Unified Voluntary Sector Fund for a further year. This will enable us to maintain our core role in Scotland until at least September 2012, including informing a rare disease plan.

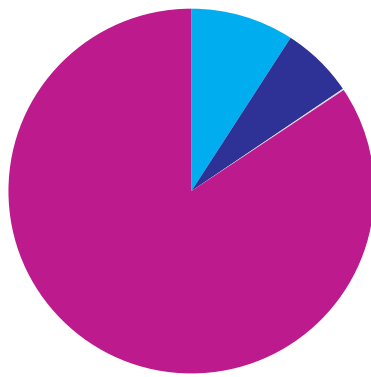
In addition to our policy work, our projects will also continue. At the

beginning of this year, we are working on eight projects and significant progress will be made on each of these in the coming 12 months. Two of our projects, Facilitating Networks and Paving the Way will draw to a close while work on Project SWAN will commence.

We will also be looking to secure further projects as competition for funding increases. We plan to build either on past projects, such as the insurance project, or conduct new areas of research which will create new opportunities to improve the lives of people living with all types of genetic conditions.

Financial Information

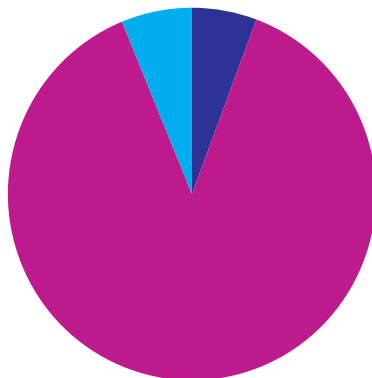
Income



- Donations: £55,721
- Membership subscriptions: £39,160
- Investment Income: £787
- Grants: £515,341

Total: £611,009

Expenditure



- Cost of generating funds: £42,232
- Charitable activities: £649,647
- Governance: £46,036

Total: £737,915

In 2010/2011, Genetic Alliance UK raised £611,009 in funds:

Source	Percentage
EU Commission	15%
UK Government	27%
Corporate	23%
Trusts and Foundations	28%
Membership	6%
Investment income	<1%
Other	<1%

Acknowledgements

Trustees

Chris Friend, Chair
Joanie Dimavicius, Vice Chair
Chris Goard, Honorary Treasurer
Jerry Brown (co-opted)
John Dart
Professor John Dodge
Jane Fisher
Sally George
Dr Fiona Hemsley
Dr Mike Knapton
Elaine Miller (co-opted) (resigned 17 January 2011)
Dr Mary Petrou (co-opted)
Dr Marita Pohlschmidt
Ruth Sands
George Scott (resigned 14 March 2011)
Richard West

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Dr Hilary Burton
Dr Alan Doyle
Caroline Harrison
Professor Shirley Hodgson
Dr Sowmiya Moorthie
Dr Liz Nelson
Robin Nott

The Genetic Alliance UK Team

Director

Alastair Kent OBE

The Team

Anna Allford - Project Officer (Ethnicity and Access)

Jessica Burke - Project Manager (Route Maps for Rare Conditions) (started July 2010)

Douglas Caldow - Project Officer (Paving the Way) (started August 2010)

Buddug Cope - Development Officer Wales

Claire Cotterill - Development Officer Scotland (left August 2010)

Benjamin Francis - Project Officer (Insurance Templates) (left August 2010)

Natalie Frankish - Development Officer Scotland (started September 2010)

Melissa Hillier - Assistant Director

Amy Hunter - Senior Research Manager (until maternity leave February 2011)

Krystle Kontoh - Project Officer (Facilitating Networks)

Alex McKeown - Project Officer (EuroGenTest II) (started February 2011)

Celine Lewis - Research Manager and Project Officer R.A.P.I.D. (started March 2011)

Lauren Limb - RDUK Research Assistant

Nick Meade - Policy Analyst

Stephen Nutt - Public Affairs Officer and RDUK Secretariat

Helen Parr - Fundraiser

Ariadne Stamtopoulou - Project Officer (Patient Partner) (left June 2010)

Allison Vitalis - Finance Officer

Julian Walker - Marketing and Communications Officer (started January 2011)

Stephanie Yin - Project Officer (Patient Partner) (started January 2011)

Medical Advisors

Professor Sir John Burn, MD, FRCP, FRCPCH, FRCOG

Professor Timothy Cox, MD, FRCP (Glas), FMedSci, FRSE

Professor Kay Davies, CBE, MRCP (Hon), FMedSci, FRS

Dr Roz A Eeles, MA, PhD, FRCP

Professor Alan Emery, MD, PhD, DSc, FRCP, FLS, FRSE (Retired June 2009)

Professor Peter Farndon, BSc, MD, FRCP, DCH

Dr Jan Gibson

Professor Nick Hastie, FRSE, FMedSci, FRS

Professor Peter Lachmann, PMedSci, FRS

Professor Norman Nevin, MD, FRCPE, FRCPath, FFCM (Belf)

Professor Mike Patton, MA, MB, MSc, FRCP, FRCPCH

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Professor Sir Keith Peters, FRS, PMedSci

Professor Martin Richards MA, PhD, ScD

Professor David Weatherall, FRS, FRCP, FRCPCH

Genetic Alliance UK would like to thank all those who have kindly supported our work during the 2010-2011 financial year

Funders:

Grants and donations:

BUPA Giving
The Big Lottery Fund
The Department of Health Section 64 and Third Sector Investment Programme
The European Commission, (Framework Programmes 6 and 7 and EAHC)
Genzyme
GlaxoSmithKline
Long Term Conditions Alliance Scotland
Medical Research Council
National Institute of Health Research
The Scottish Executive
The Wellcome Trust

Rare Disease UK

Bayer
Bio Marin
CSL Behring
Genzyme
Orphan Medicines Industry Group
Shire
Sigma Tau

Risks and Benefits Project

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GlaxoSmithKline
Novartis
Pfizer
Roche
Shire

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