Genetic Alliance UK

Supporting. Campaigning. Uniting.

ANNUAL REVIEW

2009/10

Chair's Introduction

This is the first Annual Review written under the banner of Genetic Alliance UK. We believe our new name more accurately reflects our mission to be the voice of patients and families affected by genetic disorders. Much research and thought went into the process of change and we look to engaging with members, policy makers and researchers under our new banner.

During the year the Board of Trustees also addressed key governance issues. This included risk assessment, financial and contingency planning, and the creation of a new strategic plan to achieve our goals.

The Wellcome Trust has also chosen to store our key documents and publications as part of the Wellcome Library Archives, which is immensely satisfying and will give impetus to future challenges. One such challenge is to ensure that the four UK regional governments develop plans for the management of rare diseases. Also, as the UK Government reorganises the National Health Service (NHS), Genetic Alliance UK will play a leading role in ensuring that the NHS goals of equity and excellence apply to all patients and families affected by genetic conditions.

Chris Friend
Chair of Genetic Alliance UK

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Treasurer's Report

Despite the difficult financial environment over the past year, we have been able to improve our financial position. Although donations declined dramatically since the previous year, the income through projects has continued to grow and, combined with tighter management of costs, has meant that we came very close to breakeven for the first time in a number of years.

Our ability to produce effective, influential and timely projects is a significant asset for Genetic Alliance UK. It underpins our credibility as a representative patient voice and has now begun to provide the financial stability that will allow us to build confidently on our strategic future role. Our improving financial position will ultimately allow us to reinvest in our staff, our capacity for future projects and in the resources available to us.

Rapid changes in medical and, in particular, genetic science will require us to continue to challenge the statutory framework and clinical environment. More than ever, the voice of patients needs to be heard in the debate on the future of medical sciences.

Chris Goard
Honorary Treasurer

A charity registered in England and Wales (no. 1114195) In Scotland (no. SC039299).Company Registration no: 05772999

What We Do

Genetic Alliance UK is the national charity with a membership of over 130 patient organisations supporting all those affected by genetic conditions. We aim to improve the lives of people affected by genetic conditions by ensuring that high quality services and information are available to all who need them.

Supporting

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

Campaigning

We actively 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.

"As a very small charity with limited resources, the added value of being a member of the Genetic Alliance UK is beyond measure. It enables us to reach audiences normally out of reach and to give us a collective voice that is heard, instead of being ignored."

Chris Phillips
Director, Behcets Syndrome Society

Influencing Policy

Genetic Alliance UK's campaigning role on issues of policy and practice means that much of our work is focused on influencing governments, policy makers and care providers on behalf of our members.

"The work of Genetic Alliance UK is of tremendous importance because it brings the voice of everybody affected by a genetic condition into the heart of the political debate."

Dr. Marita Pohlschmidt
Director of Research, Muscular Dystrophy Campaign

Patient Collaboration

Genetic Alliance UK facilitates and coordinates interaction between key stakeholders and patients and their families. Such interactions provide the opportunities and resources for our members to make their individual voices heard. Genetic Alliance UK also collaborates on an individual basis with member organisations, where there are specific issues and initiatives where we can help.

Profiles

Working with the HFEA

A highlight of Genetic Alliance UK's activity this year was our work on Pre-implantation Genetic Diagnosis (PGD) with the Human Fertilisation and Embryology Authority (HFEA). In addition to contributing to a redrafting of the information on the HFEA's website regarding Pre-implantation Tissue Typing (PTT), we provided input to a review of the governance of late-onset and PTT

PGD. Both of these types of PGD were regulated on a case-by-case basis rather than the usual condition-by-condition basis, i.e. each individual request is analysed rather than the 'in principle' use for a certain condition. The review was successful for late-onset conditions, but not PTT. Genetic Alliance UK is now consulted on all new condition-by-condition PGD licence applications, and we have received positive feedback from the HFEA regarding our submissions.

Committee for Advanced Therapies

Genetic Alliance UK's continuing involvement at the Committee for Advanced Therapies at the European Medicines Agency (EMA) has been another strong contribution. Our main achievement was prompting the EMA to release a statement warning of the dangers of unregulated stem cell treatments; the first time they had released such a statement.

GTAC regulatory committee for the Department of Health

Genetic Alliance UK's Director, Alastair Kent, was invited this year to become a member of the Gene Therapy Advisory Committee (GTAC), a regulatory committee for the Department of Health (DH) that examines research proposals for gene and stem cell work outside the HFEA's remit. While gene therapy has taken longer than some of its enthusiasts might have expected, it is clear that progress is being made in many areas. Stem cell therapy is also developing but in most areas it is still some way behind. Through our role in GTAC, Genetic Alliance UK will focus on ensuring that patients' perspectives are heard as these new technologies are developed.

30% of all children born with a serious congenital condition of genetic or partially genetic origin die in infancy[1]

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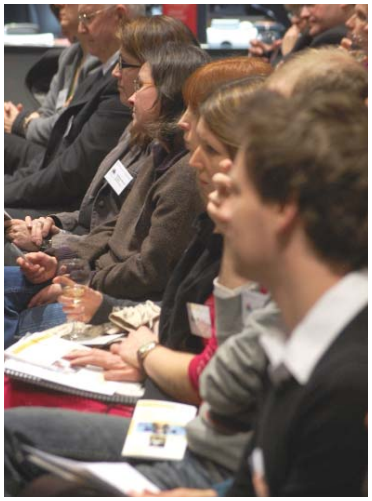
Policy Consultations Included

- The Department of Health
  - Strengthening National Commissioning
  - The Common Assessment Framework
  - The Innovation Pass Pilot
- National Institute for Health and Clinical Excellence
  - The Kennedy Study into Innovation in Healthcare
  - The Citizen's Council report
- The European Commission consultation on nanotechnology
- The European Medicines Agency's Transparency Policy
- House of Commons Health Committee Inquiry on Commissioning in England
- Nuffield Council for Bioethics consultation on medical profiling and online medicine: The ethics of 'personalised' healthcare in a consumer age
- Welsh Assembly Government
  - Proposals for the future of specialised and tertiary services
  - Community Nursing Strategy

7.9 million children worldwide are born each year with a serious congenital condition of genetic or partially genetic origin[2]

Campaigns

Animals in medical research



Genetic Alliance UK has been campaigning on the revision of EU legislation on the use of animals in medical research; leading a campaign by the patient community to ensure that the revised Directive raised the welfare standards for animals across the EU, while at the same time fostering the best possible environment for well-regulated medical research.

Working in conjunction with partner organisations, we ensured that the patient voice was communicated to Members of the European Parliament (MEPs) at all stages of the Directive's passage through the European Parliament. On behalf of the European Genetic Alliances Network (EGAN), we organised a joint statement with the European Patients' Forum, EURORDIS (Rare Diseases Europe), the European MS Platform and the European Men's Health Forum, to communicate the importance of animal research for patient benefit.

We also ran a 'Remember the Patients' campaign in conjunction with the Association of Medical Research Charities (AMRC). The campaign included an event in the European Parliament at which patients and carers were able to speak directly to MEPs about the impact the revised Directive will have on them. They gave personal testimonies of what it is like to live with a serious disease or illness such as Alzheimer's or Parkinson's, and how medical research using animals is bringing new hope and opportunities to improve their quality of life.

Shortly after the event, the European Parliament voted convincingly in support of our position. Work is continuing with the European Commission to ensure that the Parliament's amendments are taken on board but, at the time of writing, the revision of the Directive had almost been completed. It is hoped that in practice it will have little impact in the UK and will not restrict research in the EU.

Newborn screening

Genetic Alliance UK's role in supporting patient involvement with the National Services Division of NHS Scotland's Newborn Screening programme was successfully completed this year. This year, we deepened our engagement with the National Services Division (NSD). As well as being an active member of the NSD's Public Reference Group, which reviews the commissioning of specialist services in Scotland, we joined the NSD's PGD Expert Panel, which will oversee the roll-out of a PGD service in Scotland. The test for Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCAD) will shortly be added to the heel prick test in Scotland.

4.3% of babies born in the UK have a genetic condition[3]

Strengthening health services

Much of Genetic Alliance UK's policy work is focused on health services for individuals and families with genetic conditions. We contributed to the Kennedy Review on how National Institute for Health and Clinical Excellence (NICE) values innovation. In addition to submitting a written response to the review, we contributed our views at two workshops held by NICE.

We have also been setting out the patient perspective on commissioning. We submitted written evidence to the House of Commons Health Committee inquiry on commissioning in England, and our response to the Department of Health's proposal to 'Strengthen National Commissioning' was privately acclaimed by senior policy makers.

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Rare Disease UK

Genetic Alliance UK established Rare Disease UK (RDUK) in 2008 as a joint initiative with patient organisations, clinicians, academics and industry, to work towards more effective and better coordinated care and support for the estimated 3.5 million people in the UK who are affected by a rare disease, over 80% of which are genetic in origin.

We are delighted that the membership of RDUK has doubled since this time last year, and now stands at over 350. In July 2009, the Orphan Disease Industry Group Partnership (ODIGP) was established to enable pharmaceutical companies that are not members of the Association of the British Pharmaceutical Industry (ABPI) to join RDUK.

RDUK provides a single voice to drive forward a strategy for rare diseases. The adoption by European Union (EU) Health Ministers in June 2009 of the Council of Ministers' Recommendation on rare diseases was an important step forward. It meant that EU Member States have now been called upon to develop and implement plans or strategies for the treatment of rare diseases.

The Health Council's decision was in no short measure due to lobbying by numerous patient groups across

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RARE DISEASE | UK The National Alliance for people with rare diseases & all who support them

31,041 babies were born with a genetic condition in 2008; equivalent to the population of Windsor[4]

Europe. For our part, RDUK coordinated lobbying activity with the EU-wide group EURORDIS and partner organisations in other Member States. This ensured that national health ministers received consistent briefings ahead of their discussions.

Five RDUK Working Groups, comprising of experts from a variety of fields, have been established and are meeting regularly to look into various aspects of planning for rare diseases and to come up with a set of measures to evaluate the provision of services and support for people with rare diseases in the UK. Hopefully this will help governments in the UK to deliver on the EU Council Recommendation.

RDUK has planned and undertaken public affairs activities to raise awareness among key stakeholders of the importance of strategic planning for rare diseases. We have developed links with key officials in all four regional governments and National Health Services of the UK who have shown themselves willing to cooperate with us as progress is made.

Parliamentary support has also been fostered throughout the year. In the UK Parliament, we helped to establish an All-Party Parliamentary Group for Rare Diseases, which brings together Members of Parliament and Peers to discuss issues relating to rare diseases.

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Rare Disease Day

The Rare Disease Day events in the Scottish Parliament, the National Assembly for Wales and the Northern Ireland Assembly were even bigger and better than last year, with almost 60 parliamentarians and civil servants attending and significant media coverage generated.

More importantly, each event was attended by over 100 patients and patients' representatives. The events were an opportunity for our members to speak directly to parliamentarians, government officials and health service representatives.

Projects

Genetic Alliance UK has undertaken a number of projects that have gone from strength to strength, making a difference to patients and families affected by, or at risk of, genetic disorders.

30% of all children born with a serious congenital condition of genetic or partially genetic origin die in infancy[5]

EuroGenGuide and EuroGenTest, two major EU-funded projects to promote high quality, user-friendly information about genetic testing and research, in particular to people affected by genetic disorders, have been particularly effective.

EuroGenGuide

Last year saw the conclusion of Genetic Alliance UK's work on the EuroGenGuide project. Run in collaboration with 12 partner organisations from around Europe and supported by the European Commission, the project aimed to provide high-quality information about genetic testing and research to the European public; in particular to those affected by genetic disorders who might consider allowing samples of their DNA to be used for research into new therapies for treating or curing inherited disorders.

The EuroGenGuide was launched at a very successful event in Warsaw and has now been disseminated across Europe. It is available online (www.eurogenguide.eu) and in print, as well as on DVD and CD, and contains information for patients and the general public. We hope it will be a useful resource for anybody in Europe with an interest in the field.

EuroGenTest

There are now 15 EuroGenTest leaflets on 15 topics related to inheritance patterns and genetic testing, including a new leaflet on 'What does it mean to

be a carrier?' The leaflets have been translated into 27 European and ethnic minority languages, and are available as leaflets for professionals to use during genetic clinics. They are also available as HTML documents for patients and the public to access.

This year, one of the main aims of the EuroGenTest project, has been to raise awareness across Europe of the availability of this information resource. Genetic Alliance UK's Project Officer attended a range of genetic conferences throughout Europe to give presentations about the leaflets and to display them on the EuroGenTest stand. The leaflets are all available on the websites of EuroGenTest (www.eurogentest.org/patients) and Genetic Alliance UK (www.geneticalliance.org/publications), as well as through European genetic clinics and national genetics societies. The HTML patient information on the EuroGenTest website had almost 10,000 hits in March 2010, an increase of around 15% compared to the same time last year.

Genetic Alliance UK's contribution to EuroGenTest has now reached a successful conclusion. We are proud of the substantial resource made available as a result of the project and hope it will be of use to patients and the public for some time to come.

"Genetic Alliance UK is our primary source of information regarding genetic issues in the UK. If we have a question, we know they will have the answer."

Jo Grey
CEO & Chair of Trustee Board
Association for Multiple Endocrine Neoplasia Disorders (AMEND)

A baby with a genetic condition is born every half an hour in the UK[6]

Continuing Projects

Facilitating Networks

The primary aim of this project, soon entering its third and final year, is to work with small patient support groups to facilitate the development of networks of health professionals in order to improve information, care and services for patients and families affected by, or at risk of, rare genetic disorders.

Positive progress has been made during the second year of the project. Information gathered from patient support group representatives during consultations held in the project's first year has now been recorded in a uniform format, ensuring transparency and accessibility.

The networks have evolved beyond the framework we anticipated; there are now six as opposed to the projected three networks. Expert clinicians have been appointed to lead the Networks of Expertise for Cerebral Cavernous Malformations; Rasopathies Alliance Pathway; and Familial Adenomatous Polyposis.

In addition to considerable input from UK-based clinicians, the project is also attracting increasing interest from outside the UK and Genetic Alliance UK looks forward to continuing to work with patient support groups as the project moves into its final stages.

Patient Partner

Patient Partner is a three-year project funded by the European Commission's 7th Framework Programme. It is based on the belief that viewing patient organisations as equal partners throughout the clinical research process will allow for research that is better adjusted to patients' needs. The project's focus is on clinical trials for children, ethics, and biobanking.

By conducting interviews, surveys and workshops throughout Europe, we are creating two guides – one for patient organisations and one for sponsors and industry – that will provide all stakeholders with information on how to improve communication between them and how partnerships can be stimulated. Genetic Alliance UK's active involvement in the workshops has also enabled us to provide information on patients' rights, develop recommendations aimed at policy makers and to facilitate focus groups and to collect data.
http://www.patientpartner-europe.eu/

Asking Relevant Questions Project

This two year project funded by Bupa Giving focuses on patients and their needs in accessing both travel and life insurance. During the year information gathered through surveys, focus groups and interviews identified many of the common problems that patients and families are facing when applying for insurance. We have also been working with industry to identify how these issues can be overcome and have had some very positive outcomes, particularly in the travel insurance field where companies are now emerging who are actively seeking ways of addressing the unmet insurance needs of families with long term conditions. The improved flexibility in their risk calculations means that more individuals and families will be able to obtain insurance products that best meet their needs. We have also created two patient information guides on travel and life insurance to dispel some of the common myths and explain the risk rating process.

New Projects

"As members of the Genetic Alliance UK, we have access to a range of relevant information and resources that are valuable to those we support."

Toni Mathieson
Executive Director, Niemann-Pick Disease Group (UK)

RAPID

Reliable Accurate Prenatal non-Invasive Diagnosis (RAPID) is a programme funded by the National Institute for Health Research (NIHR) that aims to improve the quality of NHS prenatal diagnostic services. Genetic Alliance UK's participation, which runs until 2014, will ensure that the views and needs of parents and patients are properly accounted for well before this new technology reaches the clinic.

Work has started to look at patients' opinions and preferences about a new prenatal test currently under development. It is hoped the test will be available for women at increased risk of having children with single-gene disorders and Down's syndrome.
http://www.rapid.nhs.uk/

25% (1 in 4) patients had to wait between 5 and 30 years from early symptoms to confirmatory diagnosis of their disease[7]

Ethnicity and Access

Genetic Alliance UK has previously produced groundbreaking reports around access to genetics services for minority ethnic communities and ethnic monitoring. We have now received grant funding from the Big Lottery Fund Research Programme to run a project in partnership with the Division of Primary Care at the University of Nottingham. The project will identify the reasons for the significant under-representation of cancer referrals to clinical genetics services from minority ethnic groups. It will also look at possible solutions to this inequity.

The project will focus on bowel, breast and prostate cancer, recognised as the most common, preventable cancers with a possible genetic link. Patient recruitment has begun with the experiences of three established minority ethnic communities in England (South Asian, Black Caribbean and White Irish), to improve understanding both of patient-related contexts and perceptions and of service-related factors that facilitate or hinder access to genetic services.

Nanomed Round Table

The Nanomed Round Table is a European Commission-funded project to provide European stakeholders with a set of recommendations to support decision making on nanomedical innovations.

As well as being on the project's Steering Committee, Genetic Alliance UK led the Patients' Needs Working Group. We carried out a pilot study comprising an online survey and detailed qualitative research, in order to gain a broader understanding of patients' understanding of nanomedicine. We gathered information from patients and families and produced a detailed report (www.geneticalliance.org.uk/docs/nanomedroundtable-report_condensed.pdf) on patients' expectations of this new technology, taking into account ethical, regulatory, social and economic issues.

Based on the research, our report concluded that although patients have relatively low levels of knowledge and awareness of nanomedicine, they would like more information and see nanomedicine as an opportunity that

should be embraced. The Working Group's recommendations formed part of the overall Round Table report, which was launched in the European Parliament and has been disseminated to policy makers throughout Europe.

40% (4 in10) patients first received an erroneous diagnosis and others received none before receiving a confirmatory diagnosis[8]

Route Maps for Rare Conditions

The 'Route Maps for Rare Conditions' project is to be funded by the Department of Health, through its Third Sector Investment Programme, while the new 'Risks and Benefits' project will be funded by a consortium of pharmaceutical companies. We will also receive a small grant from Jeans for Genes for a project on undiagnosed genetic conditions. In Scotland, we have been awarded a grant for a new project funded by the Long Term Conditions Alliance Scotland.

"Genetic Alliance UK's translated genetic information leaflets are invaluable to our multi-cultural international membership.

Jo Grey
CEO & Chair of Trustee Board
Association for Multiple Endocrine Neoplasia Disorders (AMEND)

The Year Ahead

The year ahead is set to be as busy and productive as last year. RDUK will be nearing the conclusion of its initial agenda with the publication of an interim report by the Working Groups in Autumn 2010 and a final report in March 2011. Planning is also underway for our Europlan conference in November, which will provide an opportunity to gather views and opinions from UK stakeholders on the development of a strategy for rare diseases. We will also continue to work with our partners throughout Europe to share best practice in designing and implementing rare disease strategies within individual Member States.

"Through the Genetic Alliance UK, we are given the opportunity to collectively campaign, along with many other patient support groups, for improvements in health care and services for those affected by a genetic disorder; giving us a stronger voice."

Toni Mathieson
Executive Director, Niemann-Pick Disease Group (UK)

As in previous years, Genetic Alliance UK will play an active role on a number of committees. The debate on genetic test results for insurance purposes is likely to move up the agenda for certain committees and our Asking Relevant Questions project will play a particularly important role in shaping these discussions.

The coming year will also see further progress on two other existing projects – Facilitating Networks and PatientPartner – as well as the start of some new and exciting work. Our 'Route Maps for Rare Conditions' project, which will extend and develop the work we started in our earlier 'Family Route Map' project (2007),

is to be funded by the Department of Health through its Third Sector Investment Programme.

Our 'Risks and Benefits' project, to examine how patients and their families perceive the balance between the risks and benefits of new biomedical therapies, will be funded by a consortium of six pharmaceutical companies. We will also receive a small grant from Jeans for Genes for a consultation with families with children with undiagnosed genetic conditions to assess the need for their long-term support.

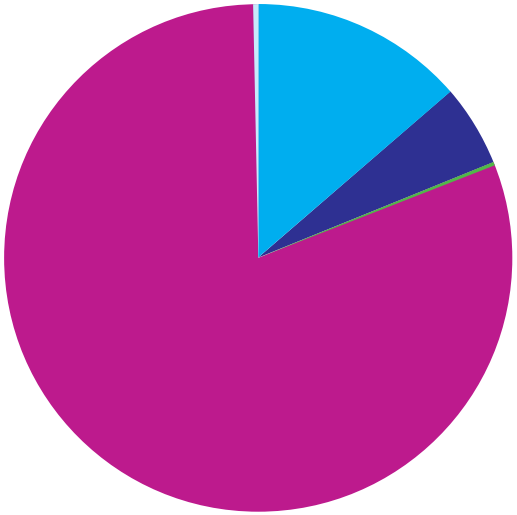
In Scotland, we have been awarded a grant for the Paving the Way to Self Management Project, funded by the Long Term Conditions Alliance Scotland, to develop a web resource containing podcasts and vodcasts.

20% (2 in 10) genetic disease patients experienced some rejection by health professionals because of their disease
In 80% of the cases the main reason was the complexity of the disease[9]

Financial Information

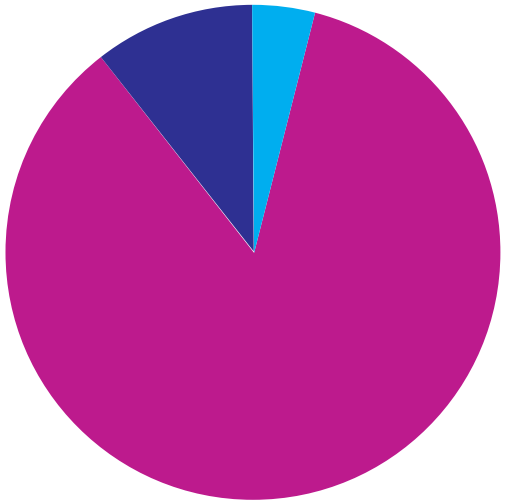
Income

Donations	£78,135
Membership Subscriptions	£28,495
Investment Income	£620
Grants	£462,500
Other	£40
Total	**£569,790**



Expenditure

Cost of generating funds	£22,896
Charitable activities	£496,074
Governance	£61,219
Total	**£580,189**



In 2009, Genetic Alliance UK raised £569,790 in funds:	
Source	Percentage
EU Commission	37%
UK Government	40%
Corporate	10%
Trusts and Foundations	7%
Membership	4%
Investment income	1%
other	1%

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Acknowledgements

Trustees

Chris Friend (Chair)
Joanie Dimavicius (Vice Chair)
Chris Goard (Honorary Treasurer)
John Dart
John Dodge
Jane Fisher
Fiona Hemsley
Mike Knapton
Elaine Miller
Marita Pohlschmidt
George Scott
Ruth Sands
Richard West
Jerry Brown (Co-opted)

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Dr Hilary Burton
Dr Alan Doyle
Dr Ian Gibson
Caroline Harrison
Professor Shirley Hodgson
Dr Liz Nelson

Director

Alastair Kent

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Policy, Campaigning and Research Team

Melissa Hillier - Assistant Director
Amy Hunter - Senior Research Manager
Lauren Limb - RDUK Research Assistant
Nick Meade - Policy Analyst
Stephen Nutt - Public Affairs Officer & RDUK Secretariat
Gillian Scott – Development Officer (Scotland) *(Left January 2010)*
Buddug Williams – Cymru Development Officer (Wales)

Finance, Fundraising and Administrative Team

Heather Law – Administrator
Helen Parr - Fundraiser
Allison Vitalis - Finance Officer

Project Team

Anna Allford - Project Officer (Ethnicity and Access)
Claire Cotterill – Project Officer (Patient Engagement)
Benjamin Francis – Project Officer (Insurance Templates)
Krystle Kontoh - Project Officer (Facilitating Networks)
Celine Lewis - Project Officer (Eurogentest & RAPID)
Alex McKeown - Project Officer (Eurogentest)
(left January 2010)
Ariadni Stamatopoulou – Project Officer (Patient Partner)

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Professor John Burn, MD, FRCP, FRCPCH, FRCOG
Professor timothy Cox, MD, FRCP (Glas), FMedSci, FRSE
Professor Kay Davies, CBE, MRCP (Hon), FMedSci, FRS
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