



autumn 2008

National Rare Disease Plan - a new opportunity for patients

In November, the European Parliament will vote on the European Commission's Communication on Rare Diseases. This communication is the result of a consultation launched a year ago (to which GIG responded), and ends a year in which the issue of rare disease has been at or near the top of the European Health agenda.

Since public health is not an area in which EU law can be passed (it is an issue in which Member States have responsibility) this communication will not be legally binding, but it will carry much political weight.

GIG, along with a group of stakeholders in rare disease, plans to use this communication to stimulate the development of a national plan for rare diseases in the UK. We are in the final stages of forming a group, preliminarily called the National Alliance for Rare Diseases, which will gather stakeholders including patients, the academic community, clinicians, and industry, to analyse the steps required to form a national plan for rare diseases in the UK. GIG will act as a secretariat for this organisation.

The group will not be starting from scratch on this issue.

"GIG would like to invite you to become a member of the National Alliance for Rare Diseases. Membership is free and open to all stakeholders with an interest in rare diseases in the UK. We would like to encourage you to take part in this exciting initiative, which will push for a full and comprehensive plan for rare diseases in the UK. For more information or to join please contact Nick Meade at nick@gig.org.uk or 020 7704 3141"

The Department of Health has already implemented a number of initiatives that will be valuable components of any coordinated action on rare diseases. Changes in the protocol for the

commissioning process for treatments for rare diseases has allowed the creation of centres of excellence for some rare diseases and the commissioning of drugs that would normally fall foul of the NHS costing criteria.

Project work by GIG, such as the Facilitating Networks project (see page 2 for more information on this work), will also be a valuable building block in the development of a coordinated national plan that can deliver tailored treatment pathways that account for the various requirements of specific conditions.

Rare diseases are a highly heterogeneous group of conditions, characterised by a high degree of complexity. The majority of the conditions are genetic in origin, but other groups such as rare cancers and auto immune disease are also included. The paradox of rare diseases is that whilst each condition is individually rare, rare diseases are not uncommon. A rare disease is defined (in the EU) as having a prevalence of less than 1 in 2 000 people. There are 15 million patients with rare diseases in the EU.

GIG expects that the EU communication will include recommendations not only for national rare disease plans in member states, but also an EU wide plan to coordinate research and treatment, utilising the critical mass of rare disease patients when viewed at the European level. This approach ties in well with another EU health initiative, the Cross Border Healthcare initiative. This will create a structure to allow European patients to travel across borders to receive the most appropriate healthcare. Specialist healthcare can then be delivered to populations large enough to make the treatment centres cost effective, whilst the cost is shared across member states.

Any national plan for rare disease for the UK must consider at the earliest possible stage the added complexity of devolved healthcare delivery in the UK. The strengths of this system must be embraced, whilst taking care to ensure there is equity across the whole of the UK. GIG will make use of our offices in Wales and Scotland and our contacts in Northern Ireland to ensure the UK's rare disease plan covers the whole country equally.

We are pleased to be involved with the evolution of a new type of healthcare for rare disease at its inception, and look forward to sharing further details of our progress in the future.

**Nick Meade
Policy Officer**

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Genetic Interest Group Website – New and Improved!

Facilitating networks of expertise with patient support group

The Genetic Interest Group is working with eight of our patient support groups on a Department of Health funded project which will facilitate the creation of networks of professional expertise in three condition areas, namely rare cancers, rare neurological and rare dermatological groups. Each network will pull together the skills and knowledge of these professionals with the intention of improving the communication between health professionals, members of multi-disciplinary teams and the patients they work with.

As the project's full time project worker I will take the lead in facilitating these eight Patient Support Groups in developing strategies which will build on their current capacity and identify sustainable ways of engaging with their network. It is envisaged that through this process we will address some major difficulties experienced by patients and their families concerning access to relevant information and optimum healthcare.

In the project's formative stage we have prioritised meeting with each of our participating support groups who will confer with their members in order to obtain an understanding of their needs and way in which they anticipate the networks will benefit them. This consultation process will continue over the next few months and will employ various methods, i.e. questionnaire surveys for patient support group members, semi-structured interviews with representatives of support groups and attending member conferences and family weekends.

This project holds very promising benefits not only for the members involved but also the wider patient and family population affected by rare genetic disorders in England. If you would like to receive additional information on this project please contact Krystle Kontoh, Facilitating Networks of Expertise Project Officer email krystle@gig.org.uk or 020 7704 3141.

**Krystle Kontoh
Project Officer**

Who is at GIG?

Head Office

- Alastair Kent - Director
- Amy Hunter - Senior Research and Policy Manager*
- Melissa Hillier - Senior Comms Manager
- Nick Meade - Policy Officer
- Helen Parr - Fundraising Officer*
- Celine Lewis - Project Officer (Eurogentest)
- Alex Mckeown - Project Officer (Eurogenguide)
- Krystle Kontoh - Facilitating Networks Project Officer
- Benjamin Francis - Insurance Template Project Officer
- Helen Roden - Finance Officer*
- Heather Law - Administrator

Regional Staff

Cardiff

- Buddug Williams - Wales / Cymru Development Officer

Scotland

- Gillian Scott - Scottish Development Officer*
- Claire Cotterill - Patient Engagement Project Officer

*part time

GIG working to address Insurance Issues affecting patients

Hello, I'd like to take this opportunity to introduce myself and the project which I will be working for the next two years at GIG. My name is Benjamin Francis and I'm working on a project called "Asking Relevant Questions" I join gig from Legal & General Life Assurance and bring with me a wealth of experience of the UK Life and Protection insurance industry and an understanding of the difficulties which often manifest between genetics and insurance. This two year action research project is funded by BUPA and picks up from a pilot initiative that took place in 2006/2007. This pilot resulted in the successful creation of a series of templates to accompany life assurance applications for four genetic conditions. I been charged with the task to advance this project to include various other insurance products and additional conditions. The initial project worked with Gauchers Disease (type1) Cystic Fibrosis, Haemochromatosis and Multiple Endocrine Neoplasia (Type 2A) and we have expanded these to include Diabetes UK, Neurofibromatosis, Cancerbackup and Breakthrough UK.

The aims of the project are to improve access to appropriate insurance products for people with complex disorders by creating an improved, more transparent framework for handling sensitive medical information in insurance decisions. The piloted templates have now been trialled and we are working closely with the Association of British Insurers to obtain their approval to ensure that the templates are widely accepted by the industry. We will then be able to work on rolling out the templates to the various patient groups as appropriate. Our hope is that by providing the Insurance companies with all of the relevant information at point application, this will negate the need for expensive and time consuming GP reports. The templates have proven themselves to be extremely useful in Life Assurance applications and the feedback from both consumers, industry specialists and underwriters has been exceptionally positive. One of the biggest issues regarding genetics and insurance comes in the form of travel insurance. This is a high volume product which many people require, but access to can often be difficult. Due to its nature, travel insurance is often sold by intermediary companies who rely on computerised underwriting systems to evaluate the risk that individuals present. At the moment there is often no margin of flexibility if an applicant has a pre-existing medical condition and many insurers will either refuse to underwrite the policy or exclude the condition from any form of coverage. This application process can often be a frustrating and confusing procedure

"GIG is very lucky and privileged to have Mr Jerry Brown as a GIG Cooptee. Jerry has over 20 years experience within the insurance industry and has helped GIG in the development of the Insurance Templates that are mentioned in this article. In the previous edition of GIG Today he kindly agreed to write a piece to help people understand Insurance Products more fully and to learn more about how insurance companies make their decisions when offering products. In the Winter edition of GIG Today Jerry will write a feature article explaining the underwriting process in more detail.

Are there any particular areas of the insurance industry that Jerry could help de-mystify? What would you like to know more about. If you would like a certain area or issue to be written about please contact Ben Francis at ben@gig.org.uk "

for people with genetic conditions as there is no referral service. If, for example a company is unable to provide cover, the consumer is often left with no further information on where to turn to next. I hope that by working with some of the back office software suppliers we will be able to gain a better understanding of how the risk analysis software functions and begin to work to effect change and an improved level of transparency within the industry.

One of the things which I committed to achieving within this project is to create a resource section on the re-designed GIG website. This section will deal with specifically with Genetics and Insurance and many of the issues within this area. I hope that this resource will provide numerous helpful and practical information about the application process. GIG is ideally placed to offer non-biased and supportive information to all people living with genetic disorders and we should utilise this position to advise our members accordingly.

If you would like to get in contact to discuss the project further, you can email me at ben@gig.org.uk or call the GIG London office.

**Benjamin Francis
Insurance Template Project Officer**

Patient's Rights: What rights would I like NHS Scotland to uphold?

The Scottish Government is launching a consultation on the creation of a Patient's Rights Bill on the 22nd September 2008 and responses are sought by the 16th January 2009.

The Genetic Interest Group are keen to speak to as many patients, families and carers as possible to find out if the Government's idea of how patients should be treated is the same as the patient's themselves.

We are organising in collaboration with Gengage (Scottish Healthcare Genetics Public Engagement Network) a consultation event to discuss the bill and gain views and opinions from patients and the wider public on the 9th December 2008 at the City Chambers in Edinburgh.

If you would like more information or would like to register for this event please contact claire@gig.org.uk. More details to follow.

The Consultation can be downloaded from: <http://www.scotland.gov.uk/Publications/2008/09/22091148/0>

Have your say on Patient Rights in Scotland.

Patient Rights, what will be looked at

The purpose of the bill is to turn the concept of a mutual NHS (outlined in Better Health, Better Care, 2007) into a reality. The bill outlines what rights patients will have and also what responsibilities patients have to NHS Scotland. The Rights discussed are: -

Access

You have the right to the same access to treatment as any other patient in Scotland.

Respect

Patients should be treated as partners whose expertise is respected. You also have the right to be treated as an individual and with dignity.

Safety

Patients have a right for their care and treatment to be safe and effective.

Communication

Patients have the right to clear communication about their health. This is particularly relevant to patients with learning disability, mental health problems, hearing or sight difficulties and people whose first language is not English.

Information

Patients have a right to up-to-date information about their treatment and care options.

Participation

Patients have the right to participate in decisions about their health and the design and delivery of services that they use / might use.

Privacy

Patients have a right to privacy and confidentiality or personal information.

Independent support and redress

Patients have a right to give the NHS feedback on the quality of care and to have independent support to make complaints.

What other rights do patients want?

An open question for extra issues to be raised.

It is hoped that by discussing with patients, carers and families these rights people will receive a better quality of service and feel that they were appropriately involved in planning their care.

Do you think that these rights will achieve that end? We would love your input please do contact Clare Cotterall.

Clare Cotterall
Patient Engagement Officer

150 Million Reasons to Act



europeanpatients'forum

The European Patients Forum launches the Patients Manifesto in European Parliament. The European Patients Forum launched in September a Patients Manifesto in the European Parliament outlining vital new measures in three fundamental areas to improve quality of healthcare across the European Union.

EPF calls for:

- Equal and timely access to safe, effective diagnosis, treatments and support;
- Better information and resources for patients to be partners in determining their care;

- A patients' voice to be heard in Brussels and throughout the European Union.

The lead-up to the forthcoming European Parliamentary Elections and new Commission is a time to set new political priorities, and commit to take action. EPF President Anders Olauson said, "Our current health systems can be unfair, divisive and fail to put the patients perspective first. We believe all patients within the EU have a basic right to equal access to quality medical treatment, regardless of where they live, their status or their income"

The Manifesto, developed by the EPF membership, who collectively represent over 150 million patients, citizens and voters 'call upon all the political groups within the European Parliament, MEPs, prospective MEPs, national representatives in EU Member States, and the new Commission, to commit to the legitimate rights and needs of patients and to make our proposals their priority.

Dagmar Roth Behrendt, MEP who hosted the launch in the European Parliament welcomed the Manifesto "This Manifesto – from patients themselves - provides a road map for all of us committed to improving healthcare in Europe. I am especially pleased to see the Manifesto calls for a comprehensive strategy on "Information to Patients" in Europe and pro-active work on health literacy – this is a crucial driver behind patients centred, quality healthcare. For more information"

www.eu-patient.eu

HFE Bill – GIG keeps the pressure on MP's

We, in the policy team at GIG, are *almost* certain that this will be the last newsletter in which we write about what we hope the HFE Bill will or will not contain. In the next issue we hope to be explaining how all of our hard work has led to a fair, safe, forward-looking piece of legislation which protects the continuation of cutting edge biomedical research in the UK.

Just as we, along with our lobbying colleagues were preparing for the Report Stage and Third Reading of the Bill back in July, the Bill was postponed until October. We now have a date, the 24th of October, for the Report Stage, and we don't expect the Bill to take up much more of the Parliamentary timetable.

By and large, this restricted schedule is a good thing from GIG's point of view. The Bill, as it currently stands is satisfactorily worded; there are no barriers to the research methods that we would like to see permitted. The debate is not over yet though.

Those that are opposed, due to ethical, moral, or religious reasons, to the current wording of the Bill have been busy over the summer and have delivered many amendments that need to be resisted.

The old issue of consent for the use of minor's cells for the creation of embryos for research has resurfaced. Our argument for this method to be permitted is strong, but it is frustrating to have resubmit it. As we have stated before, if parents cannot consent to their child's cells (normally a few skin cells) being used in the way, then research on many diseases that are lethal in childhood be permanently halted in the UK.

Many of the other amendments we must deal with are seemingly trivial, such as whether PGD can be done using protein assays rather than genetic tests. (Proteins are the products of genes, so potentially this is a genetic test and therefore permitted; but this test could also be described as a metabolic test, which would not be permitted.) The devil is in the detail, and it is imperative that the wording of the final Bill is correct. Those opposed to the new Bill will not stop their work once it is published. It is likely that the Bill will be subject to many legal challenges, as opponents test its wording in the courts.

The UK has a history of enlightened and innovative legislation for biomedical research, such as the 1990 HFE Act, and the UK laws on animal research. We look forward to explaining the latest of these laws in the next issue.

Nick Meade
Policy Officer

The GIG Forum is Your Forum

The Genetic Interest Group (GIG) has launched a new forum for its members. The forum can be found at

www.gig.org.uk/forum

How to Register on the GIG Forum

- Go to www.gig.org.uk/forum
- On the right hand side of the screen click on the word "register"
- Click "I agree to these terms"
- Complete your registration details. Username and Password as well as adding in the confirmation code.
- You will then receive an email to the address you have provided
- Click on the link that appears in that email
- You are now Registered on the GIG Forum!

NB: You will be registered as a basic user. GIG will then allocate you to become a "Member Charity" and you will be able to view the Member Forum area. This should happen within 48 hours of you registering.

Areas of the Forum

The Forum has four main areas,

Welcome to the Forum

This area contains information on how to register with the forum, Forum Rules and Forum Help.

Discussions

This contains separate areas for Everyone (eg members of the public), Members and Trustees. Members of GIG and Trustees of GIG can post in any of these three areas, however members of the public will ONLY be able to view the discussion area "For Everyone".

Regional Offices

Forum areas for Wales and Scotland. These will be used by GIGs Regional Staff and local support networks. Currently these two forums are open to everyone to view.

Events

An area for Members and GIG to post information about forthcoming events that may be of interest.

Within each of these areas there are particular "topics" such as "Ask GIG" "Share your Experiences" and "Introduce yourself". These areas allow GIG members and the public to tailor their posts on the forum. We know from our experience at GIG that many of the day-to-day issues that our members face can be similar and we hope that members will be able to offer support and guidance to other groups using our forum.

A Problem Shared is a Problem Halved

GIG is often told by groups how helpful it can be to meet other patient support groups, especially for many of our members who work from home, or run their support group in their spare time. Meeting up in person is often not possible due to a whole variety of reasons. On the GIG Forum you

can share your experiences with others who may well be in similar situations. The GIG forum will help make this an easy option.

Have your say on issues where your views can make a change

Meeting up for events and workshops can sometimes be hard, especially if people work full time, or have mobility issues. However, GIG wants to consult with all its members and we hope that we can post information onto our forum that you can comment on, even if you are unable to meet in person to discuss the issues. We hope this will extend our networks and our accessibility to all members.

A secure Area for Patients

The area on the GIG Forum that is dedicated to member charities is a hidden forum. This means that only members, GIG staff and GIG trustees can view the discussions taking place on this forum. A member of the public will not be able to see this area of the forum. We felt this was an important measure to take, so that GIG members can feel free to talk about issues openly and honestly without worrying what others who are not affected by genetic conditions may think.

Regional Developments

Both Wales and Scotland have their own area within the GIG Forum. GIG staff members in those areas will be moderating these forums and will use the forum to bring groups of patients together on particular projects and particular issues. This will be especially important for GIGs regional work as the population is very disparate and travelling to a central point can often be problematic.

The GIG Forum forms part of the new GIG website, and we hope that this new tool will be useful to all our members, as well as our other stakeholders who will be able to sign up and take part as a registered user of the GIG Forum.

Top Tip

A good place to start in the forum is within the Discussion area "For Everyone" and the Topic "Introduce Yourself". You can say a bit about you and the charity you are affiliated to.

Can't find what you are looking for?

Email Melissa (melissa@gig.org.uk)
or Nick (nick@gig.org.uk) at GIG.

Would you like to add a new SubForum topic within one of the Four overarching areas? If so please email Melissa

(melissa@gig.org.uk) or Nick (nick@gig.org.uk) at GIG.

Melissa Hillier
Senior Communications Manager

Help support GIG by shopping

I am very pleased to tell you about a new opportunity to raise much-needed funds for GIG.

We have just agreed a partnership with a new online shopping club called KidStart. We hope that working with KidStart will help us to raise some of the money that we need to support our ongoing work and, in particular, the work that we do to influence policy and service provision on behalf of our member groups.

We also hope that the partnership with KidStart will help us to significantly raise awareness and increase understanding amongst the general public of genetic disorders and what it means to have a genetic disorder in your family.

KidStart is a shopping club that works with over 200 on-line retailers and a growing number of high street shops and service companies, including Marks and Spencer, Waterstones, Expedia, Argos and PC World.

Anyone can join KidStart, free of charge. Every time you shop on line through www.kidstart.co.uk you earn savings of up to 20% of your spend, which are transferred to your Kiddybank. From your Kiddybank, you have the option of transferring your savings to GIG, to a school or to a child's trust fund or savings account.

I joined KidStart in June and so far I have saved over £40 for GIG, just by doing my regular shopping.

Collectively, KidStart members are saving tens of thousands of pounds. Even if just a small proportion of them save for GIG, it could really help us to raise money to support our work. Our page on their website could also make many more people aware of what it means to have a genetic disorder.

Please consider showing your support for the work we do by joining KidStart and saving for GIG. It costs nothing and it could really make a difference.

How to save for GIG through KidStart:

Log on to www.kidstart.co.uk/GIG

If you are not a KidStart member, you will need to register. You will be asked to accept the invitation to save for GIG. If you are already a member of KidStart, just log in and accept the invitation to save for GIG.

Go to MY PROFILE and you will see GIG as one of the beneficiaries to receive savings as you shop. You can also add a child or school that you wish to save for, and you can share your savings amongst your beneficiaries.

You can start to shop immediately and collect savings which you can view in your Kiddybank .

Every time you shop with KidStart, up to 20% of what you spend is automatically saved.

Happy shopping and saving!

KidStart
The smart way to save for children

Raise awareness of your condition through the KidStart Website

Our page on the KidStart website also offers us the opportunity to raise awareness of genetic disorders.

We have space for testimonials from our member groups, which, as well as encouraging KidStart members to save for GIG, can also tell them a little about specific genetic conditions. The testimonials will rotate, and we would like to include information about up to 10 different genetic disorders, to give a feel for the range and variety of conditions that GIG represents. We would also like to include photos of families.

If you would like to help to support GIG AND raise awareness of the condition that affects your members , please contact Melissa Hillier on 020 7704 3141 or at

Melissa@gig.org.uk

We look forward to hearing from you!

KidStart is a shopping club that works with over 200 on-line retailers and a growing number of high street shops.

RareShare –A New Site Connecting Those Affected by Rare Medical Disorders

RareShare — <http://www.RareShare.org> — is a new online network dedicated to connecting patients, families and healthcare professionals affected by rare medical disorders.

The Site, which launched in July, offers free membership to the public. While membership is not necessary to view the site, it is required in order to contribute information and to engage with other members. Those who decide to become members can be assured that their information will be kept confidential.

What differentiates RareShare from other health-related sites is its online network of communities. The Site currently hosts over 675 unique communities, each dedicated to a specific rare disorder. These communities are free to join and offer members access to several tools, including collaborative wiki-style pages, which allow members to contribute tips and other disorder-specific content, community forums, which offer members the opportunity to start new discussion threads or to contribute to existing topics, and community



experts, who help guide community members to additional reliable resources on the Web.

In the future, RareShare expects to offer its members a whole array of additional support tools. Currently under development are personal journals, which can be made public or kept private for friends and family, information about upcoming and in-progress clinical trials, a messaging system to allow members the ability to communicate privately with other members, and broader disease-group communities,

such as a community for all Lysosomal Storage Diseases.

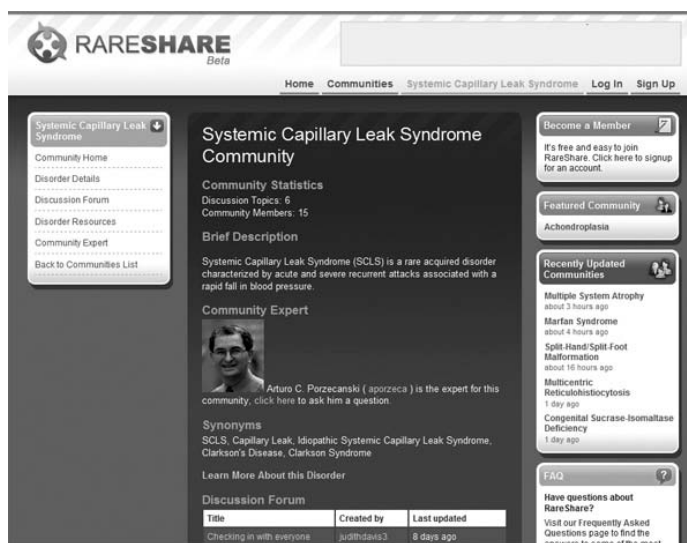
As an organization that works with medical disorders, you may be asking yourself how you can become involved with RareShare. In September, RareShare launched an exciting new initiative called the Community

Partnership Program, which provides health

advocacy and patient support organizations the chance to build public awareness through the RareShare network. Eligible organizations are offered the opportunity to place banner advertisements on RareShare for free. Interested groups can visit the RareShare blog at <http://blog.rareshare.org> for more information or email info@rareshare.org to request details about the Program.

The RareShare team is constantly brainstorming new ideas and ways to help improve the Site. Any input from outside organizations is welcome and relied upon to help make RareShare as useful as possible for its members. If you have an idea or suggestion, please email RareShare at info@rareshare.org. Your emails will be read by one of the members of the RareShare team.

— David Isserman is a graduate student at Columbia University in New York and one of the co-founders of RareShare. He can be reached by email at david@rareshare.org. —



EuroGenGuide Project Celebrates the Launch of Guide, with the Mayor of York!

September saw the launch of the first version of the EuroGenGuide project and its website, www.eurogenguide.org.uk. To celebrate the culmination of over eighteen months of hard work by the EuroGenGuide team, we held a civic reception at the York Mansion House, hosted by the Lord Mayor and Sherriff of York. Along with the EuroGenGuide team, the reception was attended by a number of patients, patient representatives, health professionals and academics from across the Yorkshire region and who have an interest in the genetics-related work that the project is carrying out. Special thanks are due to Tina Funnell from the EuroGenGuide team, who is also a Labour councillor in York and who secured the building for the reception and helped to organise the event.



EuroGenGuide Team in York



EuroGenGuide meets the Lord Mayor of York

The reception was a great success and presentations were made by myself, Councillor Tina Funnell and the Lord Mayor, and the Sherriff and his wife were kind enough to show the visiting guests around the historic building. This was of particular interest to several members of the EuroGenGuide team who had flown in from around Europe and had not been to York before. Drinks and canapes were provided and the day was a suitable event to mark the creation of the first version of the project.

Since going online at the end of July, the EuroGenGuide website has already proved popular. In September it received 11,926 hits, and at the time of writing it has received 38,745 hits in total. Currently averaging around 350 hits per day and with users viewing the site not only all around Europe but further afield in countries including China, India, America and Brazil, the early signs for interest in the project are very encouraging. Having achieved this, however, the next stage for the remainder of the project is equally, if not more, important. The challenge from now until the official launch of the finished guide at the end of 2009 is to disseminate the guide as widely as possible across Europe to patients and health professionals and get feedback from the users as to the extent to which the material meets their needs and deals with their questions. Having received feedback, we will use this in an ongoing process of review and re-drafting to improve the guide and ensure that the information is relevant for use all over Europe.

This is what will be the broad focus of the work for the rest of the project, but more immediately there are several components of EuroGenGuide which are being developed and which will be incorporated into version two of the guide, which will be produced at the end of this year. The first of these is the project website's integrated forum / newsletter / mailing list system, which is currently being constructed by the web designers, Words and People. Visitors to the site are asked if they would like to be included on the mailing list, and if they subscribe they will be sent an occasional HTML newsletter when new material or news items of relevance are posted onto the site, for which topic threads will be opened on the forum. Subscribers to the mailing list will be invited to comment and discuss the issues and the topics will either be left open if it generates a significant amount of useful discussion, or closed if it proves less popular. Those using the forum will need to provide their email address in any case, and in this way we hope to be able to increase the reach and profile of the guide and its information. The other major component is to begin translation of the guide into different European languages, so please feel free to have a look at the website and see how the project develops.

Alex McKeown
EuroGenGuide Project Officer
www.eurogenguide.org.uk

GIG Conference

Choices and Challenges – Another successful GIG Conference

For those of you unable to attend the recent GIG conference, I am delighted to be able to give you a small insight into the presentations of the day.

At this year's AGM GIG paid a fond farewell to Lady Maggie Ponder who has been GIG's Chair for the last 6 years. Maggie has worked tirelessly for GIG and provided valuable input and support helping to shape the organisation and prepare it for the future. Maggie is retaining her position as a Trustee of GIG and we used the opportunity of the AGM to wish her and her husband Bruce all the best in their well earned retirement.

Although we were sad to see Maggie go, we were very pleased to welcome Chris Friend, as GIG's new Chairman. Chris is currently the Vice Chair of GIG and we welcomed him formally into his new role and look forward to working together more closely in the coming year.

The Conference itself began after a short tea break. In our morning session *New Technologies in Prenatal Diagnosis* we heard from Dr Lyn Chitty of UCL Institute of Child Health about extremely promising new research into Non Invasive Pre Natal Diagnosis (NIPD). In fact the topic of Lyn's talk was so "hot" that she has to rush away to be interviewed by the BBC on new developments in NIPD! Alison Lashwood from Guy's and St Thomas' NHS Foundation Trust spoke about Pre Implantation Genetic Diagnosis, another new technology with promising developments for patients and how they are using this technique at Guy's. Dr Ainsley Newson, a Senior Lecturer in Biomedical Ethics from Bristol University then helped the audience to think about the many ethical issues that these new advances pose both to individuals and to society as a whole.

In the afternoon session we looked at *Perspectives on reproductive choices for people affected by genetic disorders*. Liz Pillay, a Senior Epidermolysis Bullosa (EB) Nurse spoke about the choices that adults affected by EB, a very rare and often painful genetic condition where the skin and internal body linings blister, have to consider when thinking about having a family, and we saw a film of an EB patient discussing her three pregnancies and the advice that she was given prior to having children.

Cara Scott from Ante Natal Results and Choices, spoke about the many parents who call ARC's helpline. ARC is the only national charity which provides non-directive support and information to parents throughout the antenatal testing process. Many parents call ARC's helpline in a time of great distress having had an ante natal test with an outcome that they were not expecting. Both talks were very moving and

showed both the positives and negatives of being affected by a genetic condition.

One of the main themes to emerge from the afternoon presentations and the discussion that followed was that the way in which information was conveyed to patients could have a real impact on the decisions they made and the experiences they had of interacting with the health service. Communicating often complex and devastating news needs to be done in a suitable environment. Health professionals should explain the information in an appropriate manner so that parents can be given time to make the decisions that are right for them.

Dr Hilary Burton our Key Note Speaker brought together the key issues that had been raised by both the morning and afternoon speakers and expanded what we had heard by looking at how these new technologies in genetics will impact on health services in the wider context. She spoke about three major reviews which have been carried out by the PHG Foundation, on metabolic disease, ophthalmology and cardiac genetics and discussed various issues that had been raised through these reviews and other reports, including, what are the new health needs, what do patients want, where are the gaps and what needs to happen. Hilary finally focused on how patient support groups can really help to influence the delivery of services by using their strengths to keep raising the issues that matter to them to health professionals and policy makers.



"Alastair takes questions from the floor"

"Chris Goard, Honorary Treasurer, Alastair Kent, Director and Lady Maggie Ponder, immediate past Chair of GIG"



"Cara Scott, Ante Natal Results and Choices, delivers an excellent talk"

"Dr Lyn Chitty, explains non invasive pre natal diagnosis"



Volunteers needed for research

Do you live in the North West of England?

Would you like to help improve services for families with genetic diseases or conditions?

I am carrying out research to develop ways of measuring how people with genetic diseases or conditions may benefit from seeing a geneticist / genetic counsellor or attending a genetics clinic. As part of this work, I am developing a questionnaire that will examine patients' thoughts, feelings and attitudes about the family disease or condition.

I am looking for people from families with genetic diseases or conditions to help me with this. It would mean coming to a meeting that will last for up to 2 hours to discuss the wording of the questionnaire, and to make sure that it addresses the issues that are really important to people from families with a genetic disease or condition. To help with this, you do not need to have been to a genetics clinic yourself.

There has been very little research in this area and this meeting provides an opportunity for you to help design this

questionnaire to ensure that it is easy to use and relevant to families affected by genetic diseases or conditions. The questionnaire will be used to help improve services for affected families.

The research is funded by the Medical Research Council, and has ethical approval from the University of Manchester.

If you would like to know some more about this, with no commitment to participate unless you later decide that you would like to, please contact me

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http://www.nowgen.org.uk/stories/232-dr_marion_mcallister
<http://www.medicine.manchester.ac.uk/staff/151821>

The Nowgen Centre: A Venue for Patient Support Groups

Nowgen, A Centre for Genetics in Healthcare is keen to support patients with genetic conditions and their families by providing a venue for patient support group meetings.

The Nowgen Centre...

Is next to the Manchester Royal Infirmary.
Has various meeting rooms to suit different events.
Is next to the hospital car park; with good public transport links.

How can we help?

We have a busy programme of events, meetings and courses running in the Nowgen Centre. However, when the Centre is not being used for other activities, we are able to make the facilities available to patient support groups at minimal cost. We will do our best to meet your needs; talk to our Events Team about your plans and we will help to set up the venue in the most suitable way. You may be able to borrow AV equipment from us if you arrange and agree this in advance, and agree to underwrite any losses or breakages.

What's the deal?

Generally, the Centre is heavily booked 8am - 5pm Monday to Friday, so it will usually not be possible to hold support group meetings during these times. However, please contact the Events Team to check, in case you plan to hold your event during a particularly quiet time.

If you are holding your meeting in the evening (5pm onwards) or at weekends, please contact the Events Team to book the Centre. For meetings at these times (out of hours) you will just have to pay for costs that Nowgen itself incurs: reception cover (the hourly charge is £15.70 Mon - Sat and £21.00 on a Sunday) and catering. If you want any food or drink, we would be happy to give you a quote. Under special circumstances, you may be able to arrange your own catering, but please check with us so that we may explain in full the conditions for this use and what facilities we have available.

As a condition of use, we ask that you clean up after your event and leave the venue in a good condition. We have to charge you for any breakages or when extra cleaning is required.

How do I book?

Aim to book your event at least 3 months in advance for out of hours meetings. For meeting during working hours, please contact the Events Team to discuss availability.

Contact Nowgen's Events Team (email bookings@nowgen.org.uk or phone 0161 276 5956) to enquire about room availability, and explain that you are booking on behalf of a patient support group.

Complete the forms from the Nowgen Event's Team, explaining which rooms are required and any catering or AV requirements.

Make sure you receive confirmation of your booking.

Big Lottery Funding for GIG's Family Risk Project



LOTTERY FUNDED

Earlier this month, we heard that an application we made to the Big Lottery Fund Research Programme had been successful and we will be receiving full project funding for the *Family Risks, Common Cancers and People from Minority Ethnic Groups* project. The *Family Risks* project is a three-year research study to be led by GIG, in partnership with the Division of Primary Care at the University of Nottingham. The project aims to identify why people from minority ethnic groups with a significant family history of cancer are less likely to access clinical genetics services than the mainstream UK population. The project also aims to inform the development of interventions that will improve access to clinical genetics services for people from minority ethnic groups.

We have long seen the need for a project to explore these issues. Our 1999 pilot project *Access to Genetic Services by*

Minority Ethnic Populations found a number of gaps that needed to be filled for the provision of genetic healthcare to minority ethnic groups to be adequate and recommended the introduction of ethnic monitoring and the development of culturally and linguistically appropriate approaches to genetic service delivery. In our 2003 Project, *Ethnic Monitoring in Clinical Genetics*, analysis of data in a pilot ethnic monitoring programme showed that minority ethnic groups are significantly under represented in cancer referrals to clinical genetics services in the UK. Less than 6% of all cancer referrals to clinical genetics services during the pilot period were for members of minority ethnic communities. The pilots were carried out in areas with approximately 10% minority ethnic population. This research suggests that the cancer referral rate to clinical genetics services amongst the mainstream UK population is nearly 75% higher than the referral rate for the minority ethnic population. Patients from minority ethnic groups that have, or are at risk of, cancer with a genetic component are far less likely to access screening and other services designed to mediate their higher level of risk than patients from the mainstream UK population. According to Cancer Black Care, the UK's leading cancer support service for the black and minority ethnic community "if you are black or from another minority ethnic group you are more likely to die from presentable and treatable cancers than the mainstream UK population" (www.cancerblackcare.org).

We have been seeking funding to enable us to study these concerns in more detail for several years and we are delighted that a key funding body, The Big Lottery Fund, has now recognised the importance of this work.

We are in the process of seeking Ethics Committee approval for the research methodology, and aim to start the Project in the New Year.

**Helen Parr
Fundraiser**

Genetic Interest Group Website – New and Improved!

The GIG website has had a huge facelift and will shortly be online.

This site not only contains our new Forum (please see page 6) but will also enable the valuable information that GIG produces to be delivered in a more accessible manner. We know from the feedback that we receive about the GIG site that we provide information about genetics to a wide variety of people including students, teachers, patients and health professionals. The new site will enable those people to find what they are looking for in a much easier way. The Menu Bars on the site will change from time to time, allowing GIG to add new information that again is easy to find for people that browse our site.

There are new dedicated areas for GIG Wales, GIG Scotland and for GIG Projects. Enabling members to learn more about the work we do at a click of a button. If you would like to give feedback please do use the form that is on the site and we will receive it.

