

## Roll out of Promises in the Genetics White Paper is Under Way

On 24th June 03 the long awaited white paper on genetics was launched by the Secretary of State, Dr John Reid. This was preceded by a Breakfast Briefing with the Prime Minister at 10 Downing Street attended by some of the leading figures from the clinical genetics and scientific communities and me (surely some mistake!). Both Tony Blair and John Reid were strongly supportive of genetics in medicine and the NHS, and the White Paper, as we all know, contained a number of important announcements regarding new initiatives and extra funding that will improve the capacity and ability of the NHS to make use of new genetic knowledge for the benefit of patients.

Six months on and the programmes outlined are getting underway. Bids are being submitted and evaluated for re-equipping and re-configuring NHS genetic testing laboratories, Information Management &

Technology systems are being upgraded, and plans are in hand to recruit and train the 10 GP's with a special interest in genetics who will help spearhead the transfer of genetic knowledge into primary care. A number of centres have applied to become the national coordinating centre for educating the NHS about genetics, and interesting and exciting proposals for spending the money identified to support gene therapy research have been put together. Looking ahead, we will see these plans being translated into action during the course of 2004.

Whilst miracles do not happen overnight, there ought to be tangible improvements in access to genetic services, GIG will be working closely with our members, with the Department of Health and with colleagues in the NHS to make sure this happens as quickly and equitably as possible.



Top: Alastair Kent at Number 10  
Above: All present at the Breakfast meeting

## Medical Innovation Awards

October 2003

GIG were delighted to be the one of two charities at this event on 30th October, raising money through a raffle which was drawn whilst guests were enjoying a black tie dinner.

We were delighted to raise just over £4000 which was split between ourselves and the other participating charity Cancer Research UK. As you can see from the photo, whilst, Maggie, Lucy, and myself rushed around selling tickets, Alastair was sitting down to a rather nice meal!



Alastair Kent and Jane Asher at the Medical Innovation Awards,

## Albinism Life National Conference

14th November 2003

GIG was delighted to be invited to the Albinism Fellowship Bi-Annual National Conference and to be able to have a stand in their 'market place'. The marketplace had representatives from other charitable organisations who share issues common to Albinism, and also companies who provide equipment that can be helpful for people who are visually impaired, computers which have very large text, for example highly powerful magnifying glasses for reading printed text and also reading things in the distance, there was also a company present who produce clothing that doesn't allow any sun rays through. This can be very important as some people with Albinism can burn even through

### A yearly round up from Pritti!

This has been an eventful year ± first I got hitched, and then just to prove to the world that I wasn't entering into a lifetime of domestic bliss, my new hubby and I cycled around Sri Lanka on a tandem for charity! Well not quite, a tandem might have been preferable but it was a little difficult to disguise, so we each had to settle for the regular two-wheeler variety. I have to say, friends and family were somewhat surprised when they heard about the coast-to-coast cycle around Sri Lanka, as it was so soon after our marriage, however, I can safely say that it was the most magical and challenging trip that we have ever embarked on!! Sri Lanka is beautiful - an undiscovered gem! The landscape is incredibly diverse, not to mention the hills and mountains (ouch!), and the people are amongst the warmest I have ever met. May I take this opportunity, to thank everyone that supported and sponsored us during this crazy ride!

At work things have been equally busy this year! I completed the project on 'Ethnic Monitoring in Clinical Genetics'

clothing.

GIG was pleased to be represented at this event as it gave us the opportunity to discuss some of the issues that people with genetic conditions face.

I was unfortunately a little under the weather on this day, so I hope that I didn't pass my flu on to anyone else who was attending this conference! However, through the fog, I was able to sit and listen to an amazing presentation by Caroline Casey who gave a very powerful speech about her life, coming to terms with Albinism and how she established a charity called the Aisling Foundation, initially to help fund a charitable trip across India on the back of an elephant, and which has now carried on to raise money under the charities motto of 'to prove that we all have the ability, regardless of what the label says.' The organisation continues now to 'create

inspiration through adventure create awareness of ability, not disability and to encourage employment.' It was a very uplifting talk, and showed that people can really achieve their goals, with determination, encouragement, and a lot of willpower.

For further information about the day please look on the Albinism Fellowship website [www.albinism.org.uk](http://www.albinism.org.uk)

Do you have stands from other exhibitors at your conferences? Would you like GIG to come along to distribute literature and explain a little more about genetic issues?

If you are interested please contact Melissa Winter on [melissa@gig.org.uk](mailto:melissa@gig.org.uk) or 020 7704 3141

and the full report is available on the web. As mentioned in the last newsletter, I talked about this work at the recent British Society of Human Genetics Conference 2003 in York. Further funding is now also being sought to implement the recommendations of this study - we should know in the New Year if we have been successful.

As you know the 'The Translation Project' commenced in November 2002. This London IDEAS Genetic Knowledge Park initiative is being carried out through collaboration between GIG and North West Thames Regional Genetics Centre. It aims to develop and deliver accessible patient information for London's linguistically diverse communities, and ultimately to improve patient access to genetic services. Resources are available to translate up to 27 patient information leaflets into 12 languages. Given that London is the multi-lingual capital of the world - with over 300 languages currently spoken, this project presents a significant but unique challenge.

In terms of GIG-s activities on this project to date, we have; conducted a

review of current translations of patient information, created a model for translation of genetic literature, and developed a lexicon of genetics terms that can be used in these translations. We have also attempted to assess the language needs of London population and recently held a workshop on the 1st December 2003 to seek professional advice around each of these issues. This workshop was very well attended ± and my thanks go to the all participants, especially Professor Reinier Salverda who kindly shared some of his work. On this project, I would also like to fully acknowledge the contributions of three students. Firstly, Kavita Sangha and Parul Vansadia of Brunel University, who helped to review the quality and effectiveness of current translations through, back translation and assessment by focus groups in Gujarati and Punjabi, with, lay community representatives. Our third student was Meredith Carter of George Mason University USA, who has just completed a 3-month internship with us (Sept ± Dec 2003). She helped us to develop the lexicon, looked at language needs and also participated in organising

the workshop. All three made a tremendous contribution to this project whilst bringing a lot of life to the GIG office!!

Anyway that's all for now. Hope you had a wonderful Xmas and best wishes for the New Year!!

Pritti Mehta

## A Meeting of the Family

For the very first time all of GIGs extended family met up on 20th November to discuss the work we are all now carrying out. Buddug kindly agreed to hold the first meeting at her offices in the Gene Park in Cardiff, where we

were given an excellent lunch before getting down to business. It was very encouraging to discuss our roles and to find out how we can work together in future collaborations. ± I hope you will be reading a little about the current work that everyone is doing in this edition of the newsletter and that in future publications we will be sharing such joint efforts with you all.

Melissa



Hi, we are Jo Ayres and Stuart Nicholls, members of the Nowgen (North West Genetics Knowledge Park) team.

We want to tell you a little about the aims of the Knowledge Park, what we hope to achieve, our proposed new building, and finally what we hope to be involved in personally.

Nowgen aims to provide the means by which the North West Community is best able to apply and understand genetic knowledge. It will provide information, education, guidance and training in human genetics to the public, professionals and industry. It has three core research programmes relating to the improvement of genetic services, public engagement, and ethical issues in human genetics. The team is led by Professor Dian Donnai, Executive Director, and Dr Helen Middleton Price, the Director.

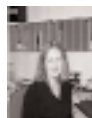
We are delighted to say that work has now begun on our purpose built, £3.5m Nowgen Centre located on the site of CMMC (Central Manchester and Manchester Children's University Hospital's Trust.). As you can see there is much work to be done before completion in late 2004.

When complete, the Nowgen Centre will offer facilities and support for

knowledge dissemination, including public reception, exhibition and interactive areas, and meeting/ teaching rooms.

## The Nowgen Centre

Which brings us on to what we hope to achieve at Nowgen: firstly we want to continue to make contact with local genetic support groups in the North West, with the intention of holding an informal support group introduction event early this year (date and venue yet to be decided). This will enable groups to come in and get a feel for what Nowgen is about, and how it may benefit their organisation. If you have any comments regarding your interest in attending this type of event, and what you would like to gain from it, please email Jo at [jo.ayres@cmmc.nhs.uk](mailto:jo.ayres@cmmc.nhs.uk) and we will be happy to take your suggestions on board.



### Jo's Role:

After completing a PGCE qualification, I most recently spent four years employed working in the Clinical Genetics Service at St Mary's Hospital in Manchester before taking up my present post at Nowgen. As Nowgen Information Officer I will be the first point of contact for

people wanting to access Nowgen's resources and will be responsible for organising ± in collaboration with GIG, CLIMB and other patient support organisations ± a paper and electronic resource of information about genetics and genetic conditions. In addition, I shall be involved in organising the exhibition and other publicly accessible areas in the Nowgen Centre. Nowgen has already made contact with other Genetics Knowledge Parks and it is hoped that this liaison will continue.

### Stuart's Role:

I have a background in genetics with a post graduate qualification in health care ethics as well as experience working as a special support assistant. As the User Engagement Officer my role is to make links with groups, such as GIG members, informing them of what Nowgen is doing and to obtain their feedback. This will be used to inform Nowgen's activities.

Nowgen's work is at the early stages, and because of this there is a great opportunity to be involved in an exciting project from the start. In the future it is hoped we will be able to tell you more about the progress of Nowgen's programme

We hope to contribute to the GIG newsletter on a regular basis but if there is anything else you want to know Nowgen please do not hesitate to get in touch.

# Patient & Public

Report 5/12/03



Anna Lane, Development Officer, Patient & Public Participation, Genetic Interest Group & Centre for Education in Medical Genetics, Clinical Genetics Unit, Birmingham Women's Hospital.

The PPI Agenda is of course part of the Government's NHS Modernisation Programme but when I started to look at the ways to involve people in the West Midlands Clinical Genetics Unit, I realised that there needed to be not only a process of change embedded around participation but also it needed to come from the top down. The Kennedy Report published following the inquiry into children's heart surgery at the Bristol Royal Infirmary indicated that 'the priority for involving the public should be that their interests are embedded into all organisations and institutions concerned with the quality of performance in the NHS: in other words, the public should be 'on the inside' rather than represented by some body 'on the outside'.

In the context of genetics the government's White Paper, 'Our Inheritance, Our Future Realising the potential of genetics in the NHS', states that 'Patients themselves will become more aware of the role of genetics and will increasingly start asking questions about familial risk, genetic tests and new therapies'.

However, it does not ask or seek to resolve the question 'how do patients become more aware of the role of genetics'? Perhaps a step in the right direction is to involve patients and the public in 'Realising the potential of genetics in the NHS'. Recommendations in the recently published report produced by Cambridge Genetics Knowledge Park, 'Addressing Genetics ± Delivering Health', call for the education of healthcare professionals in genetics to be centred on the needs of patients and for the public and patients with genetic disease to be involved in the development of educational programmes.

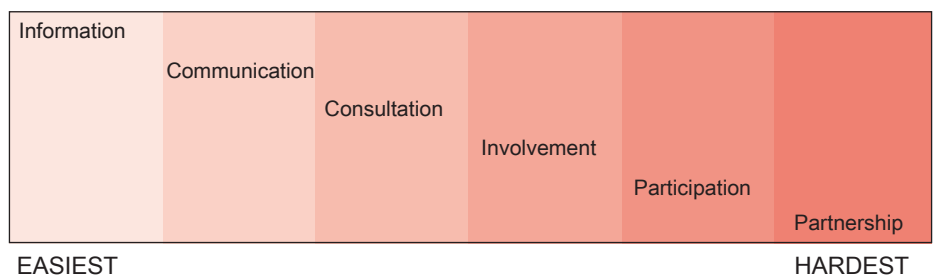
During the last few months I have been laying the foundations for the strategy that has led to a Trust-wide PPI Initiative. The Director of Nursing & Midwifery for the Birmingham Women's Hospital and I began to work together to influence the Trust Board Agenda and build this into newly developing structures. This collaborative development between the Clinical Genetics Unit and Birmingham Women's Health Care NHS Trust will provide opportunities to engage with service users and the wider community and for them to 'get involved'.

Most of the large NHS Trusts are beginning to appoint a member of staff to be responsible for PPI in the Trust, some have combined it with PALS (Patient Advice & Liaison Service), while others see it as a role for

Communications managers. There is a statutory duty placed on Trusts to consult with the public so this has driven the need to put structures in place. Having said this there is a great deal of variation in how each Trust is developing PPI and we think ours is both unique and innovative.

Much emphasis is placed on 'engagement' with people within the community served by the NHS Trust. To conceptualise engagement the diagram below represents the stages and the increasing degree of difficulty associated with them, where producing information is the easiest and working in partnership the hardest in reality.

The first stage of the PPI initiative has been to produce the leaflet, Patient and Public Involvement - Helping us to improve Services. It has been developed and shaped by staff, patients and the public to provide a direct route of communication with current, recent and future users of the Trust's services in a way in which they would like to have further or ongoing contact. Key to involving the community is the commitment and support of all staff towards partnership working. This leaflet will be used to enable Directorates to have a database of local people who want to be involved in helping us improve standards of care, develop our services and plan for the future. Personal invitations for specific projects can be generated and sent to those people who have a real interest in that area, helping to demonstrate that the Trust values their views and is committed to a continuing dialogue with the community.



People are invited through a reply slip attached to the leaflet to take part in surveys either by email, post or telephone. Alternatively, they can join a Readers' Panel to check patient information or take part in a Focus Group to discuss a topic relating to our services. Further voluntary involvement, should they wish, could be through the Women's Council, where patients and members of the public meet openly with staff to discuss services, providing a transparent, responsive mechanism for their feedback and involvement.

To further build on opportunities to hear the views of patients, the new PALS leaflet for the Trust also includes a section together with a reply slip inviting people to get involved through the new initiative. The PPI leaflet, however, was just the start and we subsequently identified administrative, information and training needs that required addressing before we could launch the initiative publicly.

### PPI Initiative Launch:

A Trust Steering Group to launch the initiative to patients, the public and voluntary groups will finalise plans for events to take place around the opening of the new Birthing Centre at the Birmingham Women's Hospital in February 2004.

Progress to date includes;

- Leaflet designed and printed - Sept 03
- Informing and involving Staff - ongoing
- Designing/developing Contacts Database - commenced November 03.

PPI Leads for each Directorate within the Trust have been identified. As the Development Officer for Patient & Public Participation I will represent Clinical Genetics. PPI leads will feed into the

new structure presented to the Trust Board that will link into the re-formed Women's Council. The Commission for Patient & Public Involvement in Health (CPPIH) appointed the statutory Patient & Public Involvement Forum (PPIF) to the Trust on December 1st 2003. PPIF Members will be encouraged to observe and/or participate at these meetings also. This process is a new one and will evolve and develop according to local health needs but importantly, for the first time it can begin to cut across social care and housing too, as involvement of the voluntary sector in a meaningful way is being encouraged through the Compact.

The Compact is the agreement between the Government and the whole Voluntary and Community Sector made in 1998. It is designed to improve their relationship for mutual advantage. There are commitments by both sides. It has principles like recognising groups are independent and have the right to campaign. The national Compact's principles have now been turned into Codes of Practice on funding, consultation, volunteering, etc. It

ensures that voluntary and community activity is supported and encouraged, including Black and Minority Ethnic groups. Local Compacts are similar agreements but at local level with councils and other public bodies.

If you feel you would like to get involved locally in the West Midlands and lend your experiences to helping develop and improve services or would like further information, please call me on 0121 623 6905 or email me at: [anna.lane@bwhct.nhs.uk](mailto:anna.lane@bwhct.nhs.uk)

### Summary

- Anna Lane works for GIG and has developed a new project with the Birmingham Women's Health Care NHS Trust.
- The project is designed to involve

## An Eastern European Working Group is Founded

patients and the public in helping to plan and improve local health services.

- There are a number of ways in which you can get involved such as taking part in a survey or reviewing information that is designed for patients.
- The government wants people to have more say in health and is encouraging this. It is called Patient Involvement.

In the framework of the European Genetic Alliance (EGA), a European Working Group for Eastern Europe was established on 23 October 2003 in Dublin, Ireland. The first and founding meeting was attended by patient representatives from Slovenia, Croatia, Poland, Bulgaria and the Ukraine.

Taking into account specific interests and problems of parents and patients in Eastern Europe, the Working Group will focus on research and development, access and reimbursement of drugs, as well as on acquiring financial resources. Considering the upcoming or planned EU membership of a growing number of Eastern European states, the Working Group will also investigate the possibilities and channels of influencing EU legislation in these fields.

We are hoping that other regionally oriented Working Groups (e.g. WG on Mediterranean Europe) will be set up in the coming year, focussing on the specific interests and problems in their own region.

Together, these Working Groups will contribute to the goals and aims of EGA, i.e. "Voicing and articulating a clear, patient focussed perspective on genetic and biotechnological issues and its ethical, legal, psycho social and cultural implications in the political, scientific and industry arena".

# What's happening in Wales?



The Wales Medical Genetic Service has received a cash injection of £1.5 million (recurrent) from the Welsh Assembly Government. This much-needed extra money will be a big boost for the Service. To make sure that the money is invested into areas of the service that will benefit Welsh families as much as possible and a group of representatives with a wide cross-section of interests is involved in this process. GIG is actively involved and is making sure that the focus of the money is to ensure best patient and family care.

Some of the money will go to strengthen existing services - providing additional staff to cope with the extra referrals referred into the Service. Funding will also be planned to put into place new tests that the service is currently not able to provide. By the next edition of GIG Today, we should know what projects will have been given the green light and I will let you know!

Over the last few weeks I've been meeting up with different representatives of support groups and charities. In November, I attended a Turner Syndrome Support Society open day at the Heath Hospital in Cardiff. This day was arranged by the hard-working TSSS team and was open to all families in the area to attend and learn more about different aspects of TS. There were several short talks by healthcare professionals with lots of open discussion. It was a very well organised and well attended day and I particularly enjoyed the opportunity to meet and chat with families. The Turner Syndrome website is: [www.tsss.org.uk](http://www.tsss.org.uk)

Earlier in 2003 the Wales Neuromuscular Network was launched. The WNN aims to bring together healthcare professionals who work with patients and families affected by neuromuscular conditions. Many medics and paramedics are from multidisciplinary areas such as neurology, orthopaedics, genetics and physiotherapy. By working together, the WNN hopes to fill in gaps of Service in different areas across Wales, improve communication and education with midwives, healthcare visitors and GPs and also assist carers with additional information and support. In late October, the Network held its first annual conference in Wrexham, North Wales. I was invited to give a short talk on my role and GIG's work. It was a valuable day for discussion and planning of future work for the Network and I really enjoyed the opportunity to mix and talk with both professionals and volunteers. If you would like to learn more about the WNN their website is: [www.walesmuscle.org.uk](http://www.walesmuscle.org.uk)

By the time you receive this edition it will be 2004 ± so blwyddyn newydd dda to you all!

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# GIG'S External Activities

A meeting of GIG's external associates was held in Cardiff on Wednesday 20th November. Each who attended presented information about their own roles and activities and the activities of the host organisations. As well as allowing everyone to get to know each other and to be able to put faces to names, this meeting highlighted several common themes and areas of interest, and made us all aware of the existence of opportunities for mutual support and collaboration. This internal networking will continue with regular meetings of this kind. The next meeting will take place in Manchester towards the end of February.

The following briefly summarises current activities nationally:

## London

### 'Ideas' ± The London Genetics Knowledge Park)

Pritti Mehta has recently published a report regarding the Ethnic Monitoring in Clinical Genetics Project. This has been extremely well received in the genetics community, and has been quoted frequently at various conferences, workshops and symposia. Pritti was invited to present a paper on the subject at the recent AGM of the British Society of Human Genetics.

GIG is currently involved in the GKP's translation project in collaboration with NW Thames Regional Genetic Centre at the Kennedy-Galton Centre at Northwick Park to develop 'best practice' models for the translation of genetic health information. A protocol has been devised by Pritti

involving not just translating genetic health information from English into another language, but also back translation to assess quality and accuracy. Relevant community consultation is also an important dimension to this protocol. The remit of this project is to translate about 27 genetic health information documents into 12 languages.

## Wales

### Wales Genetics Knowledge Park

Buddug Williams is currently establishing and consulting with a network of appropriate groups in Wales, involving those with genetic conditions and their families to generate and represent a patient viewpoint to the clinical community in Wales and the Wales Assembly Government. This involves meeting relevant groups and providing talks and presentations about GIG and our activities in Wales and the Wales GKP.

GIG is very much involved with the development of Jonathon Gray's project to establish a 'healthy living centre' ± a public engagement/education initiative to allow members of the public (the 'worried well') to seek information regarding genetic conditions without 'medicalising' them and changing them into 'patients'.

The Wales GKP is particularly focussed on inherited cardiac conditions and inherited cancer conditions. Recently, GIG agreed in principle to participate in establishing a cardiac genetic service in Wales. Further details of this will become clearer during the first quarter of 2004.

## Birmingham

### Centre For Education In Medical Genetics, Clinical Genetics Unit, Birmingham, Women's Hospital

Like Buddug in Wales, Anna Lane is very much involved in liaising and networking with a range of community and support groups.

Anna was also responsible for the organisation of the recent Genes Day event at the Thinktank in Birmingham.

Currently, Anna is involved with the Centre for Education in Medical Genetics (who act as hosts for Anna) in developing information leaflets for patients (liaising and consulting with patients and patient groups). She is very much involved in organising opportunities for patients to provide patients' perspectives of their conditions in the education of medical and healthcare professionals.

## Manchester

### 'NoWGEN' ± North West Genetics Knowledge Park

Stuart Nicholls and Jo Ayres were recently appointed in NoWGEN, and have been establishing links with relevant patient/user groups as well as liaising with clinical colleagues and researchers within NoWGEN. All this is to obtain views, and disseminate them in the appropriate directions, to influence the design, implementation and outcomes of genetics services and to inform research priorities and methods.

An electronic and paper database of patient and support groups in the area served by NoWGEN is in the process of being designed and created.

Lay-orientated genetic health information materials are in the process of being prepared, and an event is being organised in collaboration with the Progress Education Group.

Stuart is currently exploring themes

for further work in the areas of research ethics and also regarding access to genetic services by ethnic minorities.

Construction of the NoWGEN building has recently started at St. Mary's Hospital, Manchester. This is due to be completed in Autumn 2004, and Jo is involved in the development of the exhibition area. It is envisaged that this will be an education centre providing 'pathway information' and signposting for patients and families requiring further information regarding genetic conditions.

## Oxford

### Oxford Genetics Knowledge Park

GIG has agreed with Mike Parker an outline for a manual on the ethical issues arising in genetics research for members of research ethics committees. Mike's 'Ethical Issues in Genetics Research', produced for educating Australian Research Ethics Committees, is to be used as a template for this document, and it is intended that this will stimulate and provoke further discussion about the issues arising in respect to UK ethics committees and the GKPs. GIG has agreed to contribute a section on patient and research participant perspectives on the ethics of genetics research.

GIG also participates in the Oxford Genetics and Society Research Programme. The aim of the OGSP is to bring together researchers in Oxford, including those outside the GKP, who are working in the broad area of genetics and society. The group meets monthly, and these meetings have included discussions of current research and possible future research collaborations with Tom Shakespeare (Newcastle) and Professor Martin Richards (Cambridge).

T. Barclay  
Assistant Director

# 'A Baby to Save

BBC TV, December 2003

This programme told the story of the Whittaker family, and their quest to use IVF in conjunction with tissue-typing to have a baby whose cord blood could be used in a transplant to treat their existing son Charlie, who suffers from a rare blood disorder called Diamond Blackfan anaemia. Currently Charlie has to undergo regular blood transfusions and painful injections. His life expectancy is much reduced.

The Whittakers' story runs in parallel with that of Raj and Shahana Hashmi, the couple who fought to be able to create what has been called a 'saviour sibling' for their son Zain, who has thalassaemia, an inherited blood condition. The difference between the two cases is that the Hashmis, in addition to tissue typing, required a genetic test for the condition itself. This was the difference upon which the Human Fertilisation and Embryology Authority based its decision to allow the Hashmis to proceed in the UK, but not the Whittakers.

Sadly, after achieving a successful pregnancy at their third attempt the Hashmis recently announced that the pregnancy had ended in miscarriage. They are determined to try again. The Whittakers have had more luck. A Baby to Save Our Son charted their journey from refusal in the UK to the birth of their son Jamie in less than a year, thanks to the assiduous care of their UK physician, Mohamed Taranissi, and a private clinic in Chicago that carried out the procedures not allowed in the UK.

What is striking about both the Whittakers' and the Hashmis' stories is the mixture of everyday, normal hopes and fears, with a public discussion that

combines this with fears about children as 'commodities' and 'designer babies'. There is no doubt that the idea of 'saviour siblings' does raise new issues. Charlie is not just having a brother, because as he put it, 'my baby brother is going to save my life'. But of course in many ways he is also just having a brother, and they will hopefully be able to do all the things that brothers usually do together. At it was pointed out from the floor at a debate I attended recently, involving Mohamed Taranissi and Suzi Leather of the HFEA among others, if a family has a child in the conventional manner who also turns out to be a tissue match for an ill sibling, most people greet this as a marvellous thing. Can it really be so different if technology helps this to happen?

A Baby to Save Our Son concluded with the most recent decision the Whittakers have made. After waiting to be relatively sure that Jamie does not suffer from the same condition as his older brother, and to think through the implications, Charlie will undergo chemotherapy next year and a transfusion using the blood stored after Jamie's birth. A follow up programme at the end of the year will tell the story of what everyone must hope will be a successful end to their quest.

John Gillott  
Policy Officer

# Cambridge Genetics Knowledge Park Celebrates its first year.

The Cambridge Genetics Knowledge Park recently celebrated its one year anniversary, and to recognise this they held an annual symposium in Cambridge, which I attended along with other GIG staff members.

It proved to be a very informative afternoon, and a good opportunity to find out more about the work that the Knowledge Park in Cambridge are doing.

The area that I was most familiar with was the work of Dr Hilary Burton, who is one of GIG's Observers. Earlier

this year, members may remember, I organised two workshops, which many GIG members attended, where we discussed interaction between patients and the health profession and how we felt this could be improved upon, from diagnosis to treatment to the on going care received. These workshops fed into the report which Hilary was producing 'Addressing Genetics, Improving Health' which was launched on 30th September this year. This was one of the two major publications that were produced from the Cambridge Genetic Knowledge Park (CGKP) this year. This report that Hilary has published will be used at national level to establish a programme for genetic training.

As this publication involved patient participation, this was the area which I had involvement in, so it was interesting to hear about the other work

that is being carried out in the knowledge park.

There are six main areas that the CGKP have been focusing on in their first year.

- Developing CGKP partnerships and infrastructure
- Critical appraisal and systematic review
- Facilitating the transition from research to clinical practice
- Education and dissemination of genetic knowledge
- Research on the ethical, legal and social implications (ELSI) of genetics
- Public health genetics and policy developments.



The CGKP has published two major reports this year: -

- Intellectual Property (IPR's) and Genetics: A study into the impact and management of intellectual property rights within the healthcare sector, published in July
- Addressing Genetics, Delivering Health: A strategy for advancing the dissemination and application of genetics knowledge throughout our health professions, published in September.

Lecturers and researchers have given 36 lectures and published over 90 articles, papers and books since the Knowledge Park began. The team of staff work on the ethical, legal and social implications of genetic research in order to promote and disseminate genetics knowledge to the wider public. The CGKP has organised events in schools, a genetics and health Policy course as well as raising awareness within their community of the activities that are taking place. The CGKP also now has its own fully developed website [www.cgkp.org.uk](http://www.cgkp.org.uk) which will carry further information.

11th November 2003  
Annual symposium  
Melissa Winter

# Can you help provide information for siblings?

Annette Hames,  
Consultant Clinical  
Psychologist

About 15 years ago I was working as a Clinical Psychologist with two parents who had young sons with Down Syndrome and two older, non-disabled sons. One of the parents told me that she had told her non-disabled son that he had a brother with Down Syndrome, the other said that she had not. We discussed how there was very little information available for parents to help them make this decision and also little information on what they should say to children if they were going to talk about disability.

Since then I have worked with families, investigating whether parents tell children about disability, what they tell them, what questions children ask their parents, whether young children understand, and what information is available to help them understand. I have found that generally parents want to tell their children that they have a brother or sister with a disability; that the brothers and sisters of children with severe learning disability often have some understanding from the age of three years that their brother or sister is different to them; that parents sometimes worry unnecessarily about whether non-disabled brothers and sisters will cope (when in fact they do); and that it is frequently the brothers and sisters who remind parents that the disabled child is a child first and a disabled person second. One three year old, when told that her sister had Down Syndrome, asked 'but she's still my sister, isn't she?'

My research so far has been with very young brothers and sisters and I have been heartened to find so many positive findings when much research in the past with brothers and sisters has concentrated on the negative side of having a child with a disability in the family. One important piece of information that I have discovered while completing my research has been that while the healthy brothers and sisters of children with disabilities have been found to be at increased risk of suffering emotional and behavioural problems compared with other children, the chance of these difficulties

occurring is increased if there is poor knowledge and information about their brother or sister's condition. What I have found is that parents are not always able to appropriately provide information for brothers and sisters; sometimes overestimating their knowledge, other times preferring to keep information from them. In my clinical work with families I have found an American publication, Views from Our Shoes (Meyer, 1997), to be useful with the brothers and sisters of children with learning disabilities. It presents personally written accounts from brothers and sisters aged 4-18 years. A limitation of using this material has been that it contains many American words and phrases. I thought it would be useful to develop a British version of this material. I am hoping that if I can produce booklets for brothers and sisters, describing others' personal accounts of what life is like, both the highs and the lows, this will be of interest and help improve the adjustment to having a brother or sister with a disability.

If you are a parent and would like your children to be involved, or if you are a brother or sister of a child with a disability, please contact me. I am particularly interested in contacting children aged between 4 and 18 years. All I will ask you to do is complete a consent form and write a brief description, about one page, of what life is like with your brother or sister. You will need to decide whether you want to use your proper names, or if you prefer you can use made-up names. I can be contacted at the Sanderson Centre, North Avenue, Gosforth, Newcastle up Tyne NE3 4DT, telephone 0191 2196800 or email [annette.hames@nap.nhs.uk](mailto:annette.hames@nap.nhs.uk).

Thank you very much.

# contact a family

for families with disabled children

## Contact a Family - Events

Peer support days for national groups

Do you represent a support group? If so would you like to meet with others in a similar situation to you? In response to recent requests for more networking opportunities Contact a Family is organising two peer support days for groups.

## New groups: Saturday 21 February 2004

For groups which have been running for only one or two years. An opportunity to tackle some development issues and discuss ideas for the future of your groups.

## Lone paid workers: Tuesday 2

## March 2004

Are you the only paid worker for your support group? Would you like to meet with others in a similar role? An opportunity for you to meet others working alone in the running of a support group and to share ideas. The day will also include an opportunity to speak to Contact a Family's HR Administrator about employment rights, legislation and good practice.

Both days are free to support groups and will be held at Contact a Family, 209 City Road, London EC1V 1JN (nearest tube, Old Street).

For further details about either day, or to book a place please contact Liz Ranger, [liz@cafamily.org.uk](mailto:liz@cafamily.org.uk), tel: 020 7608 8715.

## Growing up, sex and the disabled teenager

Parents often feel uncomfortable talking to their child about growing up, puberty, and sex. This can be even more difficult if their child has a disability,

Now, for the first time, Contact a Family ± the national charity for families with disabled children - has joined with the Arthrogryposis Group to tackle the issue and produce one of the most comprehensive packs ever written.

Entitled Growing up, sexuality and the young disabled person, this free pack contains a series of publications offering a wealth of information and advice for

the teenager, the parent, the teacher and other professionals.

Appropriately worded for its intended audience, this user-friendly, cartoon-illustrated pack comprises a folder with separate booklets. Areas covered include self esteem, making and keeping friends, personal relationships, body image, puberty, sex education and sex and relationships. In the booklet for children and young people, young disabled teenagers pass on their tips about dealing with some of the toughest bits of growing up.

Also included in the pack is a useful list of organisations and further resources.

A free pack can be obtained from Contact a Family on 0808 808 3555 or by emailing [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk).

## The Hansard Society ±

promoting effective parliamentary democracy.

The following debate is taking place for six weeks from mid-January online at [www.tellparliament.net](http://www.tellparliament.net)

<sup>a</sup>For the first time a Parliamentary committee is asking the public what they think about an issue and we will use this information to determine the direction of the inquiry. We want to find out what you think about 'Human Reproductive Technologies and the Law'. You do not have to be an expert. All views are equally important to us.<sup>o</sup> Science and Technology Committee

New technologies could help cancer patients have children or enable lesbian couples to have their own children. Perhaps it will be possible for men to get pregnant. These ideas present many challenges: should these technologies be illegal or should it be left to doctors and their patients to decide what is best for themselves and their families?

The Science and Technology Committee have appointed the Hansard Society (as an independent, non-partisan organisation) to oversee this innovative web-based consultation.

For further information about the Hansard Society and the surveys they have carried out in the past please log onto their website at [www.hansardsociety.org](http://www.hansardsociety.org) or contact them at:

The Hansard Society  
9 Kingsway, LSE  
London WC2B 6XF  
Tel: 020 7395 4007

# Specific Eye Conditions



will be holding their Annual Conference and AGM at the Novotel,  
Broad Street, Birmingham on Saturday 28th February 2004

We have secured funding for a limited number of representatives from Specific Eye Conditions support groups for overnight accommodation.

This is an important meeting as SPECS is seeking to become a membership organisation with a Board elected and represented by member organisation groups at the AGM. If you want to ensure that SPECS reflects the needs and wants of your organisation then it is important that you attend.

To ensure that your organisation is represented contact Kay Parkinson for a booking form [k@eyeconditions.org.uk](mailto:k@eyeconditions.org.uk) or ring 01803 524238 as soon as possible. There is a £10 booking fee.

Groups representing generic interests are welcome to attend, however we do not have funds to cover these costs.

Please note also that we have no child care facilities this year.

<http://users.buy.at/>

Set up your own internet shop and receive commission on sales!

Free webshops for Community Groups at <http://users.buy.at> Here you can shop on line, with major retailers such as Amazon, Marks and Spencer, and Blackwells' plus many more and what's more it is completely free to set up your very own buy.at site. There are over 2000 community groups registered throughout the UK already. Any organisation who sets up a webshop within this site receives commission on each transaction made through their area on the site. Please do have a look on the link above and also on [www.buy.at/arc.uk](http://www.buy.at/arc.uk) for an example of a working site.

The commission that you receive comes from the retailers profit margin, and there are no administration charges at all. The site is very clear, and the money does get through to the charity. Remember it is absolutely free to sign up!

## SADS UK Conference:

Cardiac Arrhythmias,  
Research and Therapy;  
A holistic approach

June 26th- 27th, 2004

For: Families & the General Public  
& Professionals concerned with  
Cardiac Arrhythmias and  
Sudden Adult Death Syndrome

Key Speakers:

Professor Hugh Watkins  
Professor John Camm  
Dr Andrew A. Grace  
Dr Edward Blair  
Dr Michael Parker  
Dr Mary Sheppard

For further info tel:  
Anne Jolly 01277 230642  
e-mail: [info@sadsuk.org](mailto:info@sadsuk.org) -  
[www.sadsuk.org](http://www.sadsuk.org)

## The Fragile X Society May Conference

Saturday 15 May 2004 (10am-4pm)

Fragile X Society  
Scottish Family Conference  
at the Stirling Management Centre  
Topics : Fragile X Behaviour and Fragile  
X Genetics

Fragile X Society conferences are:

free to family members  
£25 for associate members  
£30 for non-members

Lunch and refreshments are provided

Crèche facilities available

For more information please contact:

The Fragile X Society  
Rood End House  
6 Stortford Road  
Great Dunmow  
Essex CM6 1DA  
Tel: 01371 875100

email: [info@fragilex.org.uk](mailto:info@fragilex.org.uk)

## The Androgen Insensitivity Syndrome Support Group (AISSG)

has a new PO Box and email address:

PO Box 429, Oldham, Lancs, OL4 4ZT. The group encourages other organisations to quote their web address ([www.medhelp.org/www/ais](http://www.medhelp.org/www/ais)) in their materials (e.g. on web sites) but \*not\* their email or street address. AISSG provides information and support to women with XY-female conditions such as Complete AIS (CAIS), Partial AIS (PAIS), XY gonadal dysgenesis (Swyer's Syndrome), 5 alpha-reductase deficiency, leydig cell hypoplasia, and to parents of affected babies/children.