

gengage news

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EVENT NEWS

Network conference, Wednesday 17th June, Glasgow

PLEASE PUT THIS DATE IN YOUR DIARIES for the annual Gengage network conference, this year to be held in Glasgow.

It will be a day-long event to allow everyone to come together and network. We wish to encourage delegates to talk with others both from within and outside their own fields, to learn from each other and gain new perspectives.

We are also keen to showcase examples of good practice.

The programme for the event is currently being compiled and we would be delighted to hear from you if you have any suggestions, or would like to run a workshop.

Please email hilary.osborne@ed.ac.uk or phone 0131 651 4750 with your thoughts.

➔ For further details, keep an eye on the 'Events' section of our website at www.gengage.org.uk

Edinburgh meeting leads to Patients' Rights Bill response

GENGAGE HAS SUBMITTED a response to the Scottish Government's consultation on a Patients' Rights Bill after gathering views at its own public consultation event held in Edinburgh in December.

The report summarises the views of over 60 participants who were at the meeting,

which was co-organised with the Genetic Interest Group (GIG). The meeting also marked the launch of Gengage and the GIG Patient Engagement Network.

Those present were asked to consider the implications of the proposed bill for healthcare genetics within

their wider experience of the NHS in Scotland.

Several themes emerged from the day's discussions. Principal among them was the need to create a partnership between patients, families, carers and the NHS, while at

Continued overleaf

NETWORK NEWS

Call for speakers

TALKING WITH MANY OF YOU over the past few months, an idea that has come up a number of times is the creation of a database of people who are willing to speak about healthcare genetics in Scotland. The database would connect speakers with opportunities to engage the public on these issues.

We're keen to respond to this apparent need.

Do you have experience of giving lectures or presentations on issues to do with healthcare genetics? Would you like to know if similar opportunities occur in the future?

Perhaps you've not spoken in public before, but would like to try. If so, we could offer you support in preparing for the role.

Or you may be a teacher or science festival organiser who is looking for a knowledgeable and enthusiastic speaker. We would be delighted to help you to find the right person.

Please contact Hilary Osborne by email at hilary.osborne@ed.ac.uk or phone 0131 651 4750.

FEEDBACK

Thoughts, please

AS THIS IS OUR FIRST NEWSLETTER we would particularly welcome your feedback on what you liked and what could be improved.

We would also like to hear from you if you can make a contribution to the next edition.

Get in touch with Hilary Osborne by email or telephone as above.

Edinburgh meeting leads to Patients' Rights Bill response

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the same time recognising the individual needs of patients, many of whom will be suffering from rare disorders.

The need for equitable care and a more 'holistic' approach were also high on people's agendas.

Hilary Osborne, Network Officer for Gengage, said:

"The high turnout demonstrates how important this is to many patients and their families. One patient commented that she 'appreciated the opportunity to be able to have a say in how the Patients' Rights Bill will be used'. This also shows the interest which was apparent in the room not just in what was in the bill but how it would be implemented and most importantly whether or not it would "have teeth" and



'You can have the right to anything, but if the healthcare professionals don't have the appropriate skills, then that right is meaningless'

actually make a difference to the patient experience."

Some of the specific issues of concern to emerge from the consultation were that the knowledge that patients and their families have about their

condition needs to be valued. Also of concern was the right to specialist services for those with rare conditions and the need for the right information at the right time for patients with these diseases.

Many attendees emphasised the need for all NHS staff, and not just those working in genetic services, to have up-to-date training and knowledge of the fast-moving field of healthcare genetics. As one patient put it: "You can have

Conference goes off with a bang

EVENT REPORT

Scottish Science Communicators conference, Glasgow

MORE THAN A HUNDRED science communicators gathered at the Glasgow Science Centre in February for a day of interactive professional development. At the start of the event, delegates were encouraged by Prof Stuart Munro, Scientific Director at Our Dynamic Earth, to use the day as an opportunity to "take a sideways look" at the ways in which science festivals, science centres and other science

communication activities can engage children, teachers and communities. He described the significant role science has played in Scotland's history and would play in its future.

The importance of continuing professional development such as that offered by the conference was emphasised by Prof Jack Jackson (HMIE and Gengage Education Sub-group Chair). Without it teachers and science communicators would not be able to keep pace with advances in science and incorporate this into their work. He went on to praise the conference as a chance to share work with colleagues and

identify possibilities for ongoing co-operation.

During the rest of the day delegates took advantage of the parallel sessions to explore topics from video podcasts to evaluation, and to discuss issues of current concern including public attitudes towards science, the role of social science and science in the headlines. The demands of the Curriculum for Excellence were examined along with promoting conceptual understanding of science and whether or not science needs to be fun in order to engage.

The presentation by Prof Richard Wiseman from the

the right to anything, but if the healthcare professionals don't have the appropriate skills, then that right is meaningless."

Although the bill focuses on rights within a hospital setting, some respondents felt a more joined-up approach was needed – both with regard to communication between all healthcare providers, and more generally with regard to patient rights over issues such as social care, education and housing.

"This group of patients often has complex needs which need to be met through a truly linked together package of care," said Claire Cotterill, GIG Patient Engagement Project Officer. "Without this, patients and their families can feel that it is the condition rather than the whole person which is being cared for."

➔ **The full submission can be found in the publications section of our website at www.gengage.org.uk**

University of Hertfordshire certainly demonstrated how science can be communicated by making it fun. One of the examples he gave was his LaughLab and the power of wanting to know the answer. By now, surely all delegates will have given in to temptation and looked up the world's funniest joke!

Finally, the day concluded quite literally with a bang when delegates were given a master class in conducting a science demonstration by Dr Bunhead.

➔ **The world's funniest joke: see LaughLab at www.laughlab.co.uk**

INTERVIEW

Professor Neva Haites, chair, Health Policy subgroup



"This is a field where Scotland is taking the lead ... Gengage may come to be seen as a model not just in Scotland, but in the greater UK"

ENGAGEMENT AROUND POLICY ISSUES will be one of Gengage's key areas of activity and Prof Neva Haites, who chairs the Health Policy subgroup, is in no doubt about the importance of this aspect of Gengage's work.

"Medical genetics is a fast-moving and highly specialised field of clinical practice and can have profound implications for patients," she says. "Gengage will provide an invaluable forum where people in policy can inform themselves of the issues so that they can take them back to their own constituencies to discuss in greater detail."

As an example, she cites the case of population genetic screening services. "Not just new tests, but existing screening programmes for conditions

such as Down syndrome may be made easier and more effective by the results of current research. But the challenge lies in knowing how best to implement these findings so as to make screening services as efficient and as sympathetic as possible. The networks created by Gengage will help to inform and educate the policy community by bringing them together with people in research and with those facing the challenges of delivering services."

The key to success will be the creation of effective networks. Prof Haites has considerable experience in this area. As Professor of Medical Genetics and Head of the College of Life Science and Medicine at the University of Aberdeen, she is adept at promoting

teamwork across all areas of the clinical and medical sciences. And as a member of the Human Fertilisation and Embryology Authority she is directly involved in the world of policy. She plainly relishes working with the other members of the Health Policy subgroup. "These are people who are known because they work very well in networks, and bring all sorts of other strengths to Gengage."

Indeed, her enthusiasm for the whole project is palpable. "I think this is a field where Scotland is taking the lead," she says, "and Gengage may well come to be seen as a model for developments not just in Scotland but in the greater UK."

■ Prof Haites was speaking to Dr Steve Sturdy

LETTER FROM THE CENTRAL TEAM

'We're keen to learn what Gengage can do to help you'



**Hilary Osborne, Gengage Network Officer,
Steve Sturdy, Gengage Grant holder**

WELCOME TO THE FIRST edition of the Gengage newsletter. We hope that you find it an interesting read and that it provides a useful update on what Gengage and those of you who are active in public engagement in healthcare genetics in Scotland have been up to in the past few months.

We're considering that Gengage's official birthday was 1st June 2008 when the Network Officer came into post to manage the development of the network. Since then we have been busy creating both the formal and informal structures which we hope will make Gengage a fruitful addition to the public engagement landscape in Scotland.

The Gengage Steering Group met in an initial form in November to set our objectives and agree a plan for taking them forward. At that stage the Steering Group had only the three sub-group chairs as members, namely Prof Sarah Cunningham-Burley (Chair, Research sub-group), Prof Neva Haites (Chair, Health Policy sub-group) and Prof Jack Jackson (Chair, Education sub-group).

Since then, other members have been recruited. Their full

details will be available shortly in the 'About Us' section of our website. We are particularly delighted to welcome Prof Kenneth Boyd, Professor of Medical Ethics at The University of Edinburgh, who has agreed to chair the Steering Group.

As many of you know, we've spent a lot of time meeting those of you already working in public engagement to find out what you're doing and hear from you what Gengage can do to support your work. We're keen to learn how Gengage can help to promote your activities and share experience and good practice with others in Scotland. We're focusing on four main areas:

Sharing experience and good practice

We work across Scotland to offer professionals who work in a wide range of fields the opportunity to learn from each other about what works and what doesn't when engaging the public in healthcare genetics.

Promoting research and evaluation

Gengage will be running workshops, seminars and training to further social

science research, to share findings with wider audiences and to consider how this can influence practice.

Training to build capacity and capability

One of Gengage's main functions is to help people develop the necessary knowledge and skills to engage the public effectively on issues to do with healthcare genetics. We are developing a training programme that will run throughout Scotland to meet these needs.

Facilitating dialogue

Our aim is not only to improve communication and make connections between individuals working to improve public engagement but also to facilitate dialogue with policy makers at the national, regional and local level. We have regular newsletters, email bulletins and a website to share this information.

Thank you for your advice, time and support so far. We look forward to working with you in coming months as the network develops and please let us know if there is anything with which we can help.

About Gengage

Gengage (the Scottish Healthcare Genetics Public Engagement Network) was established in June 2008 following recommendations in the Review of Genetics in relation to Healthcare in Scotland, chaired by Sir Kenneth Calman and published in 2006.

The review recommended that a mechanism be established to pull together and coordinate the efforts already under way in Scotland to increase public awareness, dialogue and debate on issues to do with healthcare genetics. Gengage is this mechanism and has a role to "coordinate and facilitate activity in the important area of public engagement in genetics."

The Scottish Government Health Department funds Gengage's activities in response to the recommendations of the Calman review.

Gengage is managed by the ESRC Genomics Policy and Research Forum based at the University of Edinburgh.

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