

gengage news

Issue 2 • Spring 2010

Engaging all writers – website seeks new short pieces about genes and genomics

PAGE 2



Meet the scientist – Dr Sharon Macnab on her mission to inspire the public

PAGE 3

Join our discussion: 'What should happen to your brain after you die?'

PAGE 4



'Very thought-provoking discussions' – Gengage's first annual conference was a highlight of 2009

Planning our activities for 2010

Report by Steve Sturdy, Gengage Grant holder

WELCOME to the latest edition of the Gengage newsletter.

We apologise for not having been in touch for several months but, as you may know, we were without a Network Officer pending confirmation of funding. We are delighted to say that funding has now been secured to cover the 18 months starting in February 2010, and we recently

appointed Kathryn Hunter as the new Network Officer.

Kathryn holds an LLB (Canada) and an LLM in International Law (Edinburgh), and is currently completing her Doctorate on the governance of biobanks. She was called to the Ontario Bar as a Barrister and Solicitor in 1997, and has practised in Canada in the areas of human rights and labour and employment law.

Prior to taking up her position with Gengage, Kathryn was Research

Manager at the AHRC/SCRIPT Centre for Studies in Intellectual Property and Technology Law. In this role she was involved in organising and running a number of events, including Public Interest and Health Workshops, and conferences for the European Association of Health Law, for which she was Academic Co-ordinator.

Kathryn is looking forward to taking the important work of the network forward.

CONTINUED ON PAGE TWO

EVENT NEWS

Exhibition – Inside DNA

This exciting new exhibition investigates developments in the field of human genomics and the ethical issues raised. Visitors have the opportunity to explore these developments and hear from leading researchers. The exhibition is designed to provoke questions and stimulate debate by encouraging visitors to explore issues such as the role of our genes and environment in our health, identity and evolution.

Inside DNA is currently being hosted at Sensation in Dundee until 25th April 2010. It then moves on to Rotterdam, but returns to the UK in the autumn, where it can be seen at National Museums Liverpool from 23rd October 2010 until 8th May 2011.

For further information including resources for teachers and information about special events accompanying the exhibition please see the 'Visiting' section of the Inside DNA website.

➔ www.insidedna.org.uk

FROM PAGE ONE

SINCE our last newsletter, we have had a busy time continuing to develop the network's activities and planning for the future.

The highlight was undoubtedly Gengage's First Annual Conference "A Genetic Health Service?" which was held on 17th June 2009 in Glasgow. Those who attended the event commented in particular on the range of participants, high level of turnout and quality of discussions. We were delighted with the level of support provided by both existing and new members, and look forward to the next conference in June 2010.

A report of the 2009 Gengage Conference can be found below.

Steering group

The Gengage Steering Group has met three times in the past 11 months – in March 2009, June 2009 and February 2010. The committee continues to provide invaluable advice and support in developing the activities of the network.

The Steering Group is currently finalising the 2008/9 Annual Report, which will be published shortly. A review and evaluation process for Gengage has been drawn up and an external review panel is due to meet and provide a report later this year.

The individual sub-group committees (Research, Health Policy and Education) have

also met to discuss their objectives for the coming year and have outlined plans to take these forward.

Health Policy sub-group

The Health Policy sub-group has decided to focus on governance issues connected with stored biological samples, particularly in relation to their use in research. Together with the Research sub-group, it will be holding a Brain Bank Event as part of the Edinburgh International Science Festival on 16th April 2010 at the Royal College of Surgeons.

This deliberative event will address the ethical, legal and

social issues around brain donation and brain banking.

Research sub-group

The Research sub-group is considering undertaking public engagement work around genetic testing for common complex disorders, in light of the House of Lords report on genomic medicine. It intends to explore the need and opportunities for public engagement in this area.

Education sub-group

The Education sub-group is looking at ways of improving access to education materials on healthcare genetics, including the social, ethical and legal aspects, for use in schools and elsewhere.

The sub-group is also looking at ways in which it can develop public engagement

'We were delighted with the level of support provided [for Gengage's first annual conference] by existing and new members of the network'

A 'thought-provoking' and 'inspiring' event

EVENT REPORT

Gengage Conference 2009: 'A Genetic Health Service'

SCOTLAND is keen to lead the field in promoting public engagement around healthcare genetics, as was evident from the large and lively turnout for the first annual Gengage network conference. Over ninety participants from across the country – and some from as far afield as Austria – gathered at the University of Strathclyde on 17th June to take part in a full day of talks, workshops and discussions.

The conference included plenary talks and discussions on the place of healthcare genetics in the Scottish NHS landscape, the nature and

purpose of public engagement, and the future of healthcare genetics. Workshops included sessions on how the press works and how to involve "hard to reach" groups in dialogue, as well as a discussion of how genetic services should deal with the familial character of genetic conditions. There was a chance to contribute to the Human Genetics Commission's deliberations on direct-to-consumer genetic testing.

Participants came from a wide range of backgrounds including Scottish Government, medical genetics and counselling, genetic research, patient groups, academics involved with public engagement, and many others.

Outside the programmed sessions, participants continued

discussions over lunch and coffee, and many stayed for a wine reception when the conference ended.

As one participant put it: "Overall excellent conference with some very thought-provoking discussions". Another simply said "Thank you for a very impressive and inspiring conference".

Dr Steve Sturdy, Gengage grant holder, said: "Gengage's

'Gengage's mission is to build capacity for public engagement around healthcare genetics in Scotland. Today's conference shows we have got off to a fantastic start'

mission is to build capacity for public engagement around healthcare genetics in Scotland. Gengage has only been in existence for a year, but today's conference, with its wide range of activities and participants, shows that we have got off to a fantastic start.

"There is plainly great enthusiasm for public engagement among health care providers and researchers, patients and the wider public, and we are delighted to be providing a resource that clearly addresses their needs."

➔ A full report, with links to Powerpoint presentations and notes from the workshops, can be found on our website at www.gengage.org.uk/publications-events.php?id=2

capacity across Scotland and opportunities for encouraging partnerships between those in the education and healthcare sectors. To this end, the sub-group held a meeting on 22nd February 2010 at which four thought-provoking presentations were given on teaching genetics in schools.

A Conference sub-group has also been established and is in the process of planning the next Gengage conference, which will focus on teaching genetics in schools.

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

→ info@gengage.org.uk

PUBLIC ENGAGEMENT

Calling all budding writers

The Human Genre Project is a collection of new writing in very short forms – short stories, flash fictions, reflections, poems – inspired by genes and genomics.

Launched in July 2009 and conceived by Ken MacLeod, writer in residence at the ESRC Genomics Forum, the project has already published 80 contributions on its website and welcomes further submissions as the collection continues to grow and develop.

To view the current collection, find out more about the science behind the project or to make a contribution please visit the website.

→ www.humangenreproject.com

INTERVIEW

Meet the scientist...

Dr Sharon Macnab shares her experience as a public engagement expert in her role as Science Learning Manager at Glasgow Science Centre (GSC)

I BECAME A SCIENTIST

long before I knew there was an actual word for it. I started my investigations in my garden collecting an array of minibeasts to show my reluctant sister. When considering a career path I opted for the biological sciences, studying a degree in Microbiology and then a PhD in Virology.

I have been lucky enough to experience science as an academic, primary school teacher and now as a science communicator. The roles are not as different as you may think. All require imagination, creativity and ability to multi task. You need to be adaptable as an experiment, lesson or activity can lead you on an exciting journey, with different visitor ages and stages.



‘Our mission is to inspire all to understand and explore the world around them’

In my role at GSC I have the privilege of working with scientists across all disciplines both within my team and from universities, research and industry. GSC has a lot of expertise in designing activities and in supporting scientists to engage with our visitors through matching activities to the curriculum, pitching length and content and practising modern theories of learning to ensure objectives are met.

Our mission is to inspire all to understand and explore the world around them and our visitors range from 3 year olds to adult learners. All our

visitors value encounters with science professionals working in their chosen field. They particularly enjoy finding out about what real scientists do and why.

Meet the Scientist activities help to demystify science and change perceptions that science is for individuals in Ivory Towers and something that is not relevant to them. In fact, science has never been more relevant to our everyday lives and my job gives me the opportunity to encourage people to follow their own route through science, be that understanding complex molecular structures or exploring minibeasts in their own garden – the list is endless.

● Dr Sharon Macnab is a member of Gengage’s Education sub-group

EVENT NEWS A Gengage Event

What should happen to your brain after you die?

As part of the Edinburgh International Science Festival, Gengage will be holding a deliberative event on 16th April 2010 at Surgeons' Hall, located in the Royal College of Surgeons, Edinburgh, on brain donation and brain banks.

Join us for in-depth discussion of such issues such as...

- Should we donate our brains for research after we die?
- If so, what sort of procedures should be put in place to ensure that they are used as we would wish?
- Should researchers be allowed to conduct genetic research on donated human brains?
- Should the use of donated brain material give rise to commercial gain?
- Is brain donation the same as tissue or organ donation?

A series of short presentations will be followed by facilitated round-table discussions. Participants will be asked to 'vote' on several questions.

Please book early as places are limited.

Booking details

16th April, 2010 • 1.30pm (3 hours) • Surgeons' Hall, Nicolson Street, Edinburgh

The event is FREE but must be booked through the Edinburgh International Science Festival. Online booking: www.sciencefestival.co.uk Booking hotline: 0131 553 0322.

(Please note that the Edinburgh International Science Festival Programme incorrectly states that the event is £6/£4. You will not be charged for attending this event.)

Directions to Surgeons' Hall may be found at www.surgeonshall.com/location.aspx

Programme, panellists and presentations

What are brain banks and why do we need them?

Professor Jeanne Bell, Emeritus Professor of Neuropathology, University of Edinburgh, and founder of the MRC HIV Brain and Tissue Bank and the MRC Sudden Death Brain and Tissue Bank

The UK Brain Bank Network – working together to advance our understanding of brain diseases

Professor James Ironside, Professor of Clinical Neuropathology, The University of Edinburgh, and Director of the MRC UK Brain Banks Network

Why multiple sclerosis research needs your brains

Professor Richard Reynolds, Professor of Cellular Neuroscience, Imperial College, London, and Scientific Director of the UK Multiple Sclerosis Tissue Bank

Post mortem tissue donation for research: experience of approaching bereaved families

Ms Tracey Millar, Research Nurse Co-ordinator, MRC Sudden Death Brain and Tissue Bank

All that glitters: just how special is the brain?

Dr. Martyn Pickersgill, Research Fellow, Community Health Sciences, University of Edinburgh

Avoiding the commodification of human beings in brainbanking

Dr. Austen Garwood-Gowers, Reader in Healthcare Law, Nottingham-Trent University

Chair

Professor Kenneth Boyd, Professor of Medical Ethics, The University of Edinburgh

About us

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.

Feedback

We are always keen to receive your feedback on our newsletter. We would also like to hear from you if you have a contribution for the next edition. Get in touch if you have any suggestions, either by email to info@gengage.org.uk or by telephone on 0131 651 4750.

Gengage

ESRC Genomics Forum
St John's Land
Holyrood Road
Edinburgh EH8 8AQ

info@gengage.org.uk

0131 651 4750

www.gengage.org.uk

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