

21CGH Newsletter



In this issue:

- *Scottish Family Health Study*
- *Findings from INNOGEN public consultations*
- *New Year Honours List*
- *CSO Grant Award*

New Year Honours List



Congratulations to Professor Anna Dominiczak, Professor of cardiovascular medicine, British Heart Foundation Research Centre, University of Glasgow, who was named on the New Years honours list in January 2005 with an OBE for services to medicine.

Blood Donor DNA

The CSO Biomedical and Therapeutic Research Committee awarded £181,806 to Professor David Porteous, Dr Marc Turner, Dr Shona Kerr, Dr Dave Newby, and Dr Sarah Wild to fund "Collection of a Control cohort from the Scottish population as a National DNA resource for human genetic studies".

The Scottish Family Health Study

The Scottish Family Health Study proposal was submitted to the CSO in response to the Scottish Executive's Genetics and Healthcare Initiative (GHI). Five medical schools are to join forces in a £4.4 million research study to uncover the importance of inherited genetic defects and their links to the country's abysmal record on a range of serious health problems. A total of 15,000 Scots aged between 35 and 55 will be recruited over the next three years to assess the genetic predisposition of the population to heart disease, diabetes, stroke, osteoporosis and mental health. The hope is to build the numbers to 50,000 over five years, subject to proof of principle. The findings will be used to initiate a series of further research studies into the prevention, diagnosis and treatment of key health problems that affect thousands of Scots each year. Professor Andrew Morris, of Dundee University, who is heading the study, says that Scotland now has a fantastic opportunity to see how the 25,000 genes, mapped by the human genome project, interact with the environment to either promote good health or promote disease creation.

The SFHS aims to create a visionary Scottish resource to support a diverse range of research to look at the prevention, diagnosis and treatment of illness and to promote good health. "It is clear that there isn't one single genetic defect. It is probably a range of genes which make small contributions to either good health or illness." Rhona Brankin, the deputy health minister, said: "This investment will place Scotland at the forefront of research in this area and could potentially bring long-term benefits to the Scottish people and the world at large".

More information on: <http://www.show.scot.nhs.uk /cso>

Generation Scotland: Public and Stakeholder Views

Gill Haddow, Sarah Cunningham-Burley, Ann Bruce, Sarah Parry



As reported in the July 2004 21CGH newsletter, we have been busy conducting a preliminary consultation about Generation Scotland, the proposal for a Scottish genetic databank. Researchers based at INNOGEN conducted seventeen in-depth open-ended interviews with people broadly identified by us as 'specialists' who might be broadly familiar with the concept of genetic databases (i.e., geneticists, lawyers or theologians). We followed this with ten focus groups, chosen to reflect a range of demographics (gender, ethnicity, and age), interests (patient, voluntary and civic groups), and localities (rural, semi-rural or urban).

We asked for opinions on participation, recruitment, withdrawal, access, consent, feedback (general/specific), public engagement, confidentiality and governance. Our findings are consistent with previous studies into genetic databanks; we found concern around consent, storage, access and use of genetic data. However, since we were also concerned about issues of public engagement, our results suggest more by way of possibilities for future consultations. We have fed back a full report to the specialists and focus groups and if you would like a copy of the report or have any comments to add please contact gill.haddow@ed.ac.uk (0131 650 2389) at the ESRC Innogen Centre.

Wellcome Trust Clinical Research Facility Course: Laboratory Research Techniques in Human Genetics



A new 1½ day hands-on course introducing, demonstrating and explaining practical techniques used in a human genetics laboratory will be held in the WTCRF Genetics Core Laboratories, Edinburgh. The course will include DNA extraction from blood and analysis of genetic variation. For more information please contact Dr Jane Ilesley, WTCRF Education Coordinator wtrcf.education@ed.ac.uk or download a flyer from www.wtrcf.ed.ac.uk/education/courses.htm