

# WHO'S WHO AT PEALS

Erica Haimes	Executive Director and Director of Research
Tom Shakespeare	Director of Outreach
Simon Wood	Director of Learning-elect (coming into post March 2003)
Anne Galbraith	Administrator
Fiona Hale	Action Researcher (Citizen Participation)
Lisa Matthews	Writer in Residence
Jackie Leach Scully	Researcher (Ordinary Ethics)
Tom Wakeford	Action Researcher (Citizen Participation)
Michael Whong-Barr	Researcher (Genetic Databases)
Pam Chapman	PhD student/genetic nurse specialist
Rachel Lowenson	PhD student
Stephen Macdonald	PhD student
Kathryn Milward	volunteer researcher
Lorraine Summerville	PhD student
Louise Wren	volunteer researcher

***Front cover photo: Daniel Sturgis Strip 2003 Acrylic on Canvas 61 x 122 cm***

***Photo courtesy of: Richard Salmon Gallery***

***Jury and PEALS staff photos: Simon Veit-Wilson***

# **Policy, Ethics and Life Sciences Research Institute**

## **Third Annual Report 2001-2002**

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# FOREWORD

It has been both a pleasure and a privilege to have been the Chairman of PEALS over the last three years. During this time we have seen it grow from a tender flower into a strong and flourishing plant. It has grown not only in staffing but also in its range of activities. The outreach work has always been very strong but now the increasing research funding which has been hard won, and the educational developments about to start, have broadened the scope significantly. The organisation is now on a much stronger footing financially, and we are most grateful to the various organisations including the William Leech Charitable Trust and the Northern Rock Foundation who have supported us so magnificently.

The links between the Universities of Durham and Newcastle have been strengthened by PEALS and there is now a sense of working together. We have an increasing number of joint research grants to support this, which has been one of the main achievements of PEALS over the last three years.

PEALS is now recognised nationally and internationally as a leading think tank in ethical issues and the visits from outside bodies to the North East have confirmed this position. These have included House of Lords Select Committees, the Human Genetics Commission, Wellcome Trust, UK government and scientists and policy-makers from round the world. We are now on the map and are seen to be at the leading edge of the subject. It has been great fun telling people from all over the world just what is happening in the North East of England.

None of this would have happened however without the incredible hard work and creativity of Erica Haimes, Tom Shakespeare and the PEALS team. They have shown what can be done, and I have no doubt that over the next few years they will take this even further. As I demit office it is with a touch of regret at leaving at such an exciting time. It is with confidence that I look forward to hearing of the success of PEALS in the future.

**Sir Kenneth Calman**

Chair, PEALS (1999-2002)

Warden and Vice-Chancellor, Durham University

# INTRODUCTION

In October 2002 PEALS celebrated its third birthday. We believe we have much to celebrate, having gone from one staff member to a team of seven in just three years. By the time you read this, we will be nearly a dozen people. We were delighted to be able to give public thanks at a lunch to celebrate our anniversary: both to Sir Kenneth, who has now stepped down as chair after giving invaluable support since our inception, and to our core funders the William Leech Charitable Trust and the Northern Rock Foundation, who have guaranteed our medium term survival.

This year has marked consolidation and focus as well as expansion. Our broad aim of "promoting research and debate on the social and ethical aspects of genetics and the life sciences" has been combined with a new mission statement: "to research, inform and improve policymaking, professional practice and public participation in the life sciences"

Key to this mission is our good relationship with local clinical and scientific colleagues. The arrival of the Institute of Human Genetics and the continued presence of Reproductive Medicine at the International Centre for Life have both meant that our ties with NHS and University staff have become increasingly effective. Our series of research seminars and other events have attracted members from both units and we have developed several joint research bids and sown the seeds for many others. We believe that this collaboration benefits all parties. It ensures that social and ethical dimensions of genetics and reproductive technologies are high on the professional agenda. At the same time it enables us to learn from and react to the dilemmas which daily face those working in the clinics and laboratories as well as those who experience biomedicine as patients and research participants.

The Northern Genetics Knowledge Park has consolidated our partnerships this year. Funded by the Department of Health and the Department of Trade and Industry, this network includes commercial organisations as well as the University and the International Centre for Life and is led by Professor John Burn. NGKP funding has secured the post of Director of Learning for PEALS and we have appointed philosopher Dr Simon Woods to lead on our Masters and Continuing Professional Development programmes from March 2003.

Additionally, we continue to have a close relationship with the Institute for Ageing and Health and with colleagues working in childhood disability. We have also contributed ideas on public engagement and ethics to the new Institute for Nanotechnology, to the Tesco Centre for Organic Agriculture, and to many other scientific colleagues in the region.

Within these pages, it will be clear how our range of activities plays a key role in promoting public engagement with these issues. Speaking in schools, to community groups and to the media, and organising events such as public consultation meetings and Café Scientifiques enables us to promote engagement with science and to provide opportunities for the public to express their views on policy and practice. In future, we will be working to develop more resources for teachers, students and members of the public, particularly using multi-media.

We continue to have an impact on the national and international policy and research debates. This includes key policy advisory bodies such as the Nuffield Council on Bioethics, the Nuffield Council's Working Party on the Ethics of Research on Genes and Behaviour, the Human Fertilisation and Embryology Authority, the Human Genetics Commission, the Agriculture and Environment

Biotechnology Authority and the Royal Society. In November 2001, PEALS briefed the House of Lords Select Committee on Stem Cell Research. In January 2002, members of the PEALS team had the opportunity to brief the Prime Minister about genetics and reproductive technology on the occasion of his visit to the International Centre for Life. During 2002 we also briefed Lord Sainsbury, the Minister of Science, and Dr Mike Dexter, head of the Wellcome Trust, on our work.

On the research side, PEALS members have continued to conduct research of international quality and reputation, resulting in numerous invitations to present that work to academic, policymaking and practitioner audiences at conferences across the globe. In this way PEALS aims to contribute to resolving complex contemporary questions in bioethics and biomedicine that often cut across national boundaries.

From the outset, PEALS has been keen to use its combined and diverse academic strengths to contribute to local, national and international communities. We could not do this without the support (financial, intellectual, moral) of funders, colleagues and friends throughout the North East and we are therefore glad to have this opportunity to thank you all.



Professor Erica Haimes  
*Executive Director*  
*Director of Research*



Dr. Tom Shakespeare  
*Director of Outreach*

# FUNDED RESEARCH ACTIVITIES

## I

### Northern Rock Foundation professorial funding

From the outset, PEALS has been ambitious to use an integrated programme of research, outreach and teaching activities to engage with the practical activities of policy-making, professional practice and public involvement in the life sciences. We have aimed to use these activities to benefit local and regional communities as well as to have an impact on national and international debates.

To achieve this, we need a core team of senior full time dedicated staff. We are extremely grateful therefore to the Northern Rock Foundation for funding a five year full time Director of Research post, to go alongside the five year funding provided by the William Leech Charitable Trust for our Director of Outreach post. We shall also have a five year Director of Learning post funded by the Northern Genetics Knowledge Park from March 2003.

In our discussions with the Northern Rock Foundation, we stressed several aspects of our work. First, we aim to bring together the social sciences and humanities to create an evidence-based bioethics. Pure philosophical enquiry can become abstract and irrelevant, whilst empiricism without sound argumentation may also fail to affect policy or practice. The PEALS mission is to bring philosophers and social scientists together in dialogue with scientists, medics and policy-makers, in order to create a coherent and fully informed approach. Second, we are committed to public engagement, to bringing the benefits of research to the widest possible audience, and to reflecting public concerns in the academic work we undertake.

Although the Foundation does not usually fund university research, these distinctive

features of the PEALS project persuaded the Northern Rock Foundation trustees to commit £300,000 to PEALS over a five year period. This has been used to secure the full time contribution of Professor Erica Haines as Director of Research for PEALS. As one of the core founders of PEALS, Erica has helped shape its direction from the outset. As an academic with an international reputation for high quality research examining the social, legal and ethical aspects of reproductive technologies and of genetic identity, she possesses the appropriate expertise to develop the extended programme of research combining social science and bioethics, which is central to the mission of PEALS. We have also been able to invest in a research assistant for PEALS, and to provide a working budget to pump prime new research initiatives. Having committed so much of her time and energy to the formation of PEALS, it is fitting that Erica takes her place as full time Director of Research, and as Executive Director of PEALS as a whole.

We are very grateful to the Northern Rock Foundation for making the next phase of PEALS development possible, and look forward to working with them over the next five years and beyond.

## II

# A comparative study of participation and non-participation in the North Cumbria Community Genetics Project: an update

It is well known that genetic researchers hope to revolutionise health care through an improved understanding of the causes of disease. One major tool in realising this ambition is large-scale genetic databases. These link personal medical information with DNA samples to produce data to inform understandings of gene-disease associations. Plans by the Wellcome Trust, Medical Research Council and Department of Health to build a national genetic database (known as UK Biobank) have recently attracted much attention. However, very little is known about the views and concerns of those who have been asked to donate samples and information to genetic databases. To assist policy makers, we need to know the views of such people, particularly their reasons for participating or not. What values do people draw upon when deciding whether or not to donate to genetics research?

This question has been at the heart of a Wellcome Trust project undertaken by Erica Haines and Michael Whong-Barr. Their study focuses on donor and non-donor views of the North Cumbria Community Genetics Project (NCCGP), a local biobank in West Cumbria. With the consent of mothers concerned, the NCCGP collects (i) blood and tissue samples from the umbilical cord of newborn babies; (ii) maternal blood samples; and (iii) information about health and lifestyles. The aim of the NCCGP is to assist the identification of gene-disease associations, and the impact of environmental factors on those associations.

Haines & Whong-Barr have now completed fieldwork and are in the process of analysing interviews with potential donors, researchers responsible for the DNA bank and Cumbrian community groups. Initial findings have been presented and/or published at many national and international events. These include:

### Publications

Competing perspectives on reasons for participation and non-participation in the North Cumbria Community Genetics Project, in B.M. Knoppers (ed.), *DNA Sampling: Ethical, Legal and Social Issues*, Kluwer International: New York, forthcoming 2003.

Sociology, ethics, and genetic databases, in R. Tutton & O. Corrigan, (eds.) *Donating, Collecting and Exploiting Human Tissue: Social and Ethical Dimensions of Genetic Research*, London: Routledge, forthcoming 2004.

### Presentations

European Association for the Study of Science and Technology (EASST), York University, August 2002

Third International DNA Sampling Conference, University of Montreal, September 2002

Judge Institute of Management Studies, University of Cambridge, September 2002

Cardiff Genetics and Society Research Group, University of Wales College of Medicine, July 2002.

Ethical and Social Issues in Human Genetic Sample Collections: A seminar on work in progress, Centre for Ethics in Medicine, University of Bristol, January 2002.

Other publications and conference presentations are in the pipeline. The study will be completed by Easter 2003.

### III

## DIY Citizens Jury

*"Consultations are often full of good intentions, but are based on the preconceived ideas and agendas of the commissioning body. Here, ordinary people have been in charge - there is no commissioning body. The steering group is in control of the process. The facilitators are there to do what we want"*

Marjorie Taylor, DIY Jury Steering Group

The Newcastle DIY Citizens Jury began when a group of older people from around Tyneside came together in March 2002 to start planning the first ever Do It Yourself Jury. Sixty people discussed ways of improving policies that affect older people. "Most of us hadn't met each other before, but what we had in common was that we wanted to change things for the better for older people", says Bob Watson, another Steering Group member.

Over the following weeks the Steering Group met seven or eight times to decide what the subject of the jury should be. Usually in a citizens jury a local authority or a government body decides the subject. But in this Do It Yourself Jury, it was ordinary people who were in charge.

The Steering Group chose a topic and experts with a range of perspectives and knowledge. The subject of our jury was falls among older people, in particular the development of new health technologies that might reduce falls.

Falls are not an issue commonly thought about by most people. Despite being older people themselves, none of the steering group had been involved in discussions on falls before. Having been present at the hearings of the jury, they heard how falls can be the most important trigger that can turn an able-bodied older person into a disabled or infirm one.

### The Steering Group's Observations on the DIY Jury

- 1) Consultations are often full of good intentions, but are based on the preconceived ideas and agendas of the commissioning body.
- 2) Here, ordinary people have been in charge - there was no commissioning body. The steering group is in control of the process. The facilitators are there to do what we want.
- 3) This is an experiment. We are making mistakes, but learning from them.



*DIY Jury*

We are making a handbook and video for others who want to run their own DIY Jury and there has already been much interest in this.

By the end of September 2002, the jury's hearings were in full swing. The jury's final verdict can be downloaded from [www.peals.ncl.ac.uk](http://www.peals.ncl.ac.uk). The Joseph Rowntree Charitable Trust has wholly funded this project.

## IV

# DEMOCS - Deliberative Meetings Organised by Citizens

PEALS has been a collaborator on an innovative new method of public engagement, led by the New Economics Foundation and funded by the Wellcome Trust. Invented by Perry Walker of NEF, DEMOCS are intended to be a way of enabling ordinary citizens to debate issues and to register their views. This approach dovetails with the PEALS aim of promoting participation and consultation in science, and we were delighted to be part of the team of facilitators, community development workers and bioethicists who worked on the project.

DEMOCS are intended to supplement and complement existing ways of communicating science and promoting public policy input. Whereas a citizens jury takes considerable organisation - even with the PEALS DIY Citizens Jury kit! - DEMOCS should be accessible to any group of people, without a facilitator or external input. A DEMOCS should work like a game. A small group - perhaps in a workplace, a neighbourhood, or just a few friends - receives a copy of the DEMOCS kit on the particular issue that they want to understand and comment on. Then they play through the process, using cards printed with information and questions, and after a few hours they are able to arrive at an informed view, which can then be forwarded to policy-makers or consultative bodies.

That's the theory. Fine-tuning the practice took a year's worth of workshops, phone calls, emails and thought. We set out to make a DEMOCS on stem cell research, subsequently producing resources on pre-implantation genetic diagnosis, and latterly on over the counter genetic testing - at the request of the Human Genetics Commission, who are currently consulting on this issue. Various iterations of the game followed, with debate raging over the merits of cards over post-it notes, whether

role-playing brought the issues alive or just intimidated people, what the exit strategy was, and other questions of facilitation and participation.

Eventually, a beta version emerged which was then subjected to exhaustive testing by people at the New Economics Foundation offices, by attendees at the British Association Festival of Science, by members of the PEALS network in Newcastle, by a group of homeless people and by others - 300 in total. A questionnaire circulated to many of these participants revealed:

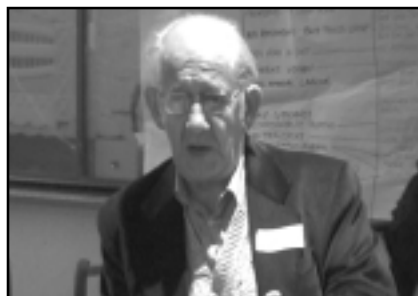
- \* 52% said their understanding of views different from her/his own had increased;
- \* A large majority (89%) managed to 'identify dilemmas' in their 'thinking and feeling'. However, only just over a quarter resolved them;
- \* Most people (70%) felt 'slightly clearer than before' on 'the rights and wrongs of stem cell research'. 12% felt much clearer than before, while 17% felt no clearer than before;
- \* There was considerable enthusiasm for playing a DEMOCS on another subject.

The full report on this pilot project is available from PEALS on request. NEF are currently trying to raise funding for further development of the DEMOCS methodology and PEALS hopes to remain involved in the project.

## V

### Weekends Away for a Bigger Voice

*"Oh, yes, consultation! We've been consulted to death round here." Community worker in Newcastle, where the proposed demolition of terraced houses and displacement of their residents in favour of riverside apartments has been accompanied by what the Council claims is one of the largest ever local government consultations.*



John Smith, Marian Bailey and George Haglington (pictured) were three out of forty participants involved in the "Weekends Away for a Bigger Voice"; where PEALS invited ordinary people to come and spend a night in a local hotel, and have a chance over two days to discuss and develop their views. The process was designed to feed into the government's Policy Commission on the Future of Farming and Food, and was commissioned by the National Consumer Council and funded by DEFRA and the Food Standards Agency.

Though the focus was on the future of food, the process was as much about challenging conventional models of public consultation as it was about what we grow in our fields and cook in our kitchens. Not only did these processes give an opportunity for people to come up with their recommendations, it also acknowledged their right to a bigger voice. "We arrived thinking that we didn't know anything about food and farming," says Marian, "but the Weekends made us realise that they need the views of people like us, and we have something important to say."

Rejecting the charge of apathy against his community, George points out, "We're not apathetic, we're frustrated." "We've been

consulted that many times, but it doesn't make any difference what we say, because in the end nobody takes any notice of our point of view - and they've already made the decisions," adds Marian.

But the PEALS Weekend Away process was different. According to John, "It gave us the confidence to challenge the people who make the decisions." He was among a group of participants that met with Lord Whitty of DEFRA and Suzi Leather of the Food Standards Agency to get the government's response to their recommendations. Another group of participants made a presentation on the Weekend Away to their local Primary Care Trust, whilst another made a video of the process.

John, George and Marian have now decided they want to start their own version of the Weekend Away to get other people from their area involved in having their say on issues that affect them. They have set up Outlook NorthEast, a new initiative that is bringing in people who would not normally have a voice in the local or national policy arena, and they are working to find better ways of getting their voice heard.

The National Consumer Council's report is available from [www.ncc.org.uk](http://www.ncc.org.uk).

## VI

# Ordinary Ethics: moral evaluation of the new genetics by non-professionals

In April 2002, Dr Tom Shakespeare and Dr Sarah Banks (Centre for Applied Social Studies, University of Durham), who had previously collaborated on the Wellcome Trust's Youth and Community Work project, got together with Dr Jackie Leach Scully (University of Basel) to submit a new proposal to the Wellcome Trust's Medicine in Society scheme, to explore how members of the public decide what they think of innovations in genetics and reproductive technology. Reviewers' comments were very positive, and funding was awarded for two years from October 2002.

This research project builds on previous work by Jackie with members of the UK Religious Society of Friends, and on her current work with Arbeitsstelle für Bioethik in Basel, Switzerland. There is a substantive literature from philosophers, social scientists and policy-makers on the ethical aspects of genetics. There is also research on public attitudes to genetics and on the divide between professional expertise and public ignorance. However, we lack understanding of how lay publics make ethical evaluation, or the moral values on which public attitudes are based. The aims of the current project are to investigate the process by which non-professionals construct an understanding of a bioethical problem and the models they use to do so, and to compare

these with the professional equivalents.

The methodology for this project involves creating a 'vignette' of a contemporary bioethical dilemma, for example pre-implantation genetic diagnosis. The professional bioethical literature on the topic will be reviewed and the views of leading clinicians will be explored through interviews, to create a set of 'expert' opinions. A series of focus groups or group interviews will be held with members of the public, during which there will be discussion of the vignette. Subsequently, follow-up interviews with individuals will allow the issue to be explored in greater depth. Participants will be drawn from different age groups and will broadly reflect other demographic variables such as gender, class and religion.

In terms of outcomes, we hope that a deeper understanding of moral evaluation will generate more nuanced public debate, help bridge the lay/professional divide and contribute to the knowledge base needed for effective public engagement. The project should also contribute to the bioethics discipline, providing more empirical data on how individuals and groups perceive and evaluate moral issues, and how moral judgements are made in real life, to supplement the theoretical work of normative ethics.

# House of Lords Select Committee on Stem Cell Research

On 22nd January 2001 the House of Lords voted to approve the Human Fertilisation and Embryology (Research Purposes) Regulations 2001. The Regulations, which were approved by the House of Commons on 19th December 2000, extend the purposes for which research can be carried out on early embryos under the regulatory regime contained within the Human Fertilisation and Embryology Act 1990, to include:

- \* Increasing knowledge about the development of embryos;
- \* Increasing knowledge about serious disease; and
- \* Enabling any such knowledge to be applied in developing treatments for serious disease.

It is hoped that these new regulations will enable research to be carried out into the development and use of CNR (Cell Nuclear Replacement) in the therapeutic treatment of diseased tissues and organs and in developing effective treatments for mitochondrial diseases. Serious concerns were, however, raised during the House of Lords debate about the use of CNR and although the Regulations came into effect on 31st January 2001, a House of Lords Select Committee was thereby appointed to report on the issues raised by human cloning and stem cell research with a view to the Regulations being reviewed once the Committee had reported.

In response to the Select Committee's call for evidence, a small group of experts from the Universities of Durham and Newcastle was established under the umbrella of PEALS for the purpose of making a written submission to the Committee on the legal and ethical issues raised by the amended Regulations. The group, which met under the Chairmanship of Professor Sir Kenneth Calman, was drawn from

a wide range of disciplines, including genetic and molecular biology, reproductive medicine, sociology, philosophy, theology and law. In the submission of evidence the group did not seek to put forward any one particular view as to the ethics of conducting stem cell research on embryos, but rather sought to clarify and elucidate the more important ethical and legal questions to which the amended Regulations give rise. A broad range of important issues was therefore addressed, including:

- \* The potential therapeutic benefits to be gained from the research;
- \* The safety and efficacy of CNR techniques;
- \* The terminology being employed in the debate and the implications thereof;
- \* The inclusiveness of the debate;
- \* The appropriate prioritisation and deployment of health care resources, both nationally and globally;
- \* The moral status of the embryo;
- \* The wider consequences of taking what may appear to be only small incremental steps in the development of these techniques, including the increased risk of cloning techniques being employed for reproductive purposes; and
- \* The effectiveness of the current legal regime in preventing the development and use of practices deemed ethically unacceptable, such as human reproductive cloning.

Following the submission of the group's written evidence, the House of Lords Select Committee visited Durham in November 2001 to hold an informal closed meeting with the members of the group to discuss in greater detail the questions and issues which had been raised.

The House of Lords Select Committee published its report in February 2002. In general terms the Committee gave its support to the new Regulations stating that it was not persuaded that all research on human embryos should be prohibited and, in particular, that there was 'a strong scientific case' for continued research on embryonic stem cells. It did, however, conclude that embryos should not be created specifically for research purposes (as opposed to the use of surplus embryos from IVF treatment) unless 'there is a demonstrable and exceptional need that cannot be met by the use of surplus embryos.' The current limit whereby all embryos used in research must be destroyed at 14 days was unequivocally endorsed. As regards the use of CNR for potential therapeutic purposes, the Committee again concluded that there was 'a sufficiently serious and important objective' to justify the use of the technique, subject to the same condition that an embryo is not created using CNR 'unless there is a demonstrable and exceptional need that cannot be met by the use of surplus embryos.' The issue of reproductive cloning was addressed by the Committee with the high risk of abnormalities,

the 'unacceptability of experimenting on a human being' and 'the familial and child welfare considerations' being identified as the most important ethical objections. The Committee gave its full support to the Human Reproductive Cloning Act 2001 which makes reproductive cloning a criminal offence and called on the Government to support any moves towards an international ban.

The House of Lords Select Committee Report is not of course the end of this debate. Embryonic stem cell research and the development and use of CNR remain extremely controversial. Recent claims by the Raelians that a woman has successfully given birth to a cloned baby girl have further fuelled the discussion, with calls for an international ban on human cloning, at least for reproductive purposes, growing ever louder. Members of PEALS will continue to contribute to this fundamentally important national and international debate.

Sonia Harris-Short  
Lecturer in Law  
University of Durham.

# REVIEW ESSAY: PEALS IN PRINT

Anne Kerr, Tom Shakespeare, Suzy Varty (Illustrator) *Genetic Politics: From eugenics to genome*, New Clarion Press, 2002; 224 pages.

Jackie Leach Scully, *Playing in the Presence: Genetics, Ethics and Spirituality*, Quaker Books, 2002; 116 pages.

Robert Song, *Human Genetics: Fabricating the future*, Darton, Longman & Todd Ltd, 2002; 149 pages.

Members of the PEALS team have published three new books in the past year. The titles have much in common. They each focus on ethical issues in human genetics and seek to widen discussions on these issues by considering the larger context in which debates are constructed. All three books are immensely readable.

*Human Genetics*, by Robert Song (Durham) addresses a wide range of issues, including reproductive genetics; therapy/enhancement distinctions; and the role of justice and community in behavioural genetics, insurance and patenting. Newcomers to the field, and undergraduates, will find the glossary and introduction to genetics helpful. The real strength of the book, however, lies in Song's approach to ethical analysis. The author does not limit his moral inquiry to the application of the appropriate principles or methods to a given problem. Instead, he extends his evaluation to the wider social and cultural context. 'Ethics needs to be embodied', Song writes, and that involves an understanding of 'some of the causal factors - the attitudes, beliefs and existential commitments, as well as medical, scientific and commercial pressures - which have governed developments in genetics' (p. 5).

In identifying these factors, Song is indebted to American theologian Gerald McKenny. Both refer to the broad social context in which technology is created and shaped as the 'Baconian Project' (p. 114). This refers to a dual and distinctly modern moral imperative: the

drive to eliminate human suffering and the expansion of human autonomy. The problem, according to Song, is that the very worthiness of these goals masks the way in which they can become 'distorted' and 'integral to ideals which are morally problematic' (p. 118). Misplaced ideals, for Song, are those that depreciate the value of human community and foster consumerist attitudes towards both children and the body. Song has serious reservations about techniques such as pre-implantation diagnosis or cloning. In his view, the commitment to eliminating suffering gives rise to the assumption that all suffering is pointless, and therefore that there is little value in attempting to find meaning in it. In medicine, the desire to control fate (through choice) leads uneasily to an instrumentalisation of the body as an object that is manipulable in accordance with individual tastes and preferences.

In challenging the necessity of technology, Song believes that the role of Christians is not so much to make a contribution to the debate, as to 'live the difference' (p. 128). This includes an affirmation of human limits and recognition of the very fragility of life. It includes a resistance towards seeing the body as something to be transcended or manipulated in accordance with desire. Anyone who is uneasy with the reign of technology is likely to find value in Song's diagnosis of the current situation and his counter-narrative to our understandings of the human good.

Kerr (York) & Shakespeare (Newcastle) address similar themes. *Genetic Politics* is a useful

introduction to topics such as the history of eugenics, the cultural representation of genetics, and the perspective that the social model of disability brings to current technologies. With Song, the authors argue that eugenics is an 'emergent property' of the prevailing structure of reproduction (p. 6).

In this structure, the authors claim that choice is restricted by the attitudes and ethos of medical professionals, who tend to provide prospective parents with biased information regarding their pregnancy. The authors are particularly concerned with the slippery slope of prenatal services, such as ultrasound and amniocentesis. They highlight three consequences of the primacy of 'genetic choice' (p. 142). These consequences are: a cultural and professional atmosphere that makes it difficult to carry disabled babies to term; the risk of discrimination in insurance or employment due to third party access to genetic information; and a greater surveillance of the health of the population, which could have potential costs for human liberty. The authors offer a wide range of solutions, including better regulation of technology through democratic means and increased public participation in policy decisions - what they refer to as 'bioethics from the ground up' (p. 188). Kerr & Shakespeare also advocate having parents of potentially affected fetuses learn more about disability before deciding on termination.

Scully (Basel) is the only trained scientist of the three. She writes from the perspective of a

geneticist, yet combines this with her long-standing interest in religion - particularly the Quaker faith. *Playing in the Presence* is an original and entertaining analysis. Scully does not seek to advocate concrete solutions to problems in genetics. Rather, the strength of her analysis is in her ability to capture the deep and often neglected connections between science and spirituality.

The book's central theme is that science can best be understood through the metaphor of 'playing' (p. 47). Using examples from music and from child's play, Scully attempts to show how the values of respect, relationship and enjoyment are, or at least *ought* to form, essential components of the scientific attempt to 'comprehend the workings of the outside world' (p. 60). She writes that science, like play, interweaves logical thought with imaginative, intuitive, emotional and strategic qualities. Her conclusion is that by adopting a more playful attitude towards genetics, we may come to better appreciate the rules that must be observed in maintaining a healthy and respectful relationship both with other humans and with nature in general. Scully believes that Quakerism helps in this endeavour by reminding us of the interplay between God, self, and Other.

Taken together, these titles nicely reflect PEALS' goal to influence policy and practice in the life sciences, particularly in genetics and reproductive technologies.

*Reviewed by Michael Whong-Barr (parts of this review have been published elsewhere in Whong-Barr, M., 2003. 'Review: Human Genetics and Genetic Politics'; New Genetics and Society, 22).*

# OUTREACH ACTIVITIES

## **Café Scientifique National Development Project**

The Café Scientifique concept, based on a French idea, was developed in the UK by Duncan Dallas, formerly producer of Horizon, Head of Science at Yorkshire Television and founder of the XYTV production company. Duncan began holding discussions on science controversies in a Leeds wine bar in the late 1990s. When PEALS began, one of our first initiatives was to found a Tyneside Café Scientifique in January 2000. We have since had 27 meetings in Newcastle's Live Theatre, at which a prestigious line-up of scientists and science writers have debated subjects as diverse as astrophysics, genetics, artificial intelligence and marine science. Audiences average 60, but sometimes over 100 members of the public have turned out for a stimulating talk and a vigorous debate.

In 2001, Duncan Dallas and Tom Shakespeare were successful in winning a grant from the Wellcome Trust to roll out the Café Scientifique concept across the British Isles. Dr Teresa Anderson, a highly experienced scientist and science communicator was appointed as the national development worker for a three year term, and has since worked hard to promote the format in different places. Leeds, Newcastle and Nottingham were the core of the network, but have now been joined by Oxford, Norwich, Edinburgh, Lancaster, Orkney and several in London. There are now more than twenty café scientifiques, each taking a slightly different form, and meeting in communities across the country.

The distinctive feature of this project is that Café Scientifiques are independent of the science establishment. Most are run by non-scientists. By taking science out of the academic sphere, and by fostering critical debate, Café Scientifiques are meeting the

need for accessible, spin-free discussion. Even the fashion magazine Vogue has endorsed the concept, writing: "Café Philosophe and Cafe Scientifique (two groups that meet in cafes, restaurants and theatres across the country) steer clear of dull theorising by addressing provocative, current issues to an eager young crowd..."

Our next ambition is to create a European network of Café Scientifiques, and we are considering an application to the European Union Sixth Framework Programme. For an insight into the latest situation, plus resources for those aiming to start their own Café Scientifiques, check out the website at: [www.cafescientifique.org](http://www.cafescientifique.org).

## **Philosophy for Children in Newcastle**

Philosophy for Children is an innovative way of promoting critical thinking with children and young people. Sessions start with a story or a picture, and students are encouraged to ask questions and debate issues which arise from the story presented. The features of P4C thinking skills lessons are: there is no one single correct answer; no one has all the answers; dialogue is more important than answers. The effects of P4C are to increase young people's self esteem and confidence, to improve listening skills, to nurture collaboration and creativity, and to foster questioning and reasoning skills.

P4C has been widely adopted by different education authorities, including Northumberland. When Mary Midgley enlisted PEALS to help her promote philosophy, our working group decided that the best way forward was to provide some basic training in P4C techniques for school teachers and science educators in other parts of our region who might benefit from the methodology. To this end, PEALS

organised a level one training course, delivered by James Nottingham, at the International Centre for Life between March and June 2002. As well as free training sessions for teachers, there were free P4C sessions for local schools and for families who attended Saturday open sessions. The Midgley Fund provided the sponsorship, the International Centre for Life provided the venues and PEALS recruited participants.

The background motivation for PEALS was our concern with public debate on ethics and with the teaching of science. We believe that P4C is an excellent way of contributing to both areas. With James Nottingham, we developed P4C resources to enable discussions to cover bioethics issues and these were the basis of the training course. Later in the year, PEALS contributed to a regional conference organised by SAPERE (Society for Advancing Philosophical Enquiry and Reflection in Education) and the University of Sunderland. We hope to develop further resources for classroom teaching of bioethics in future.

## **Science Week 2002**

A chance meeting on a London Underground platform led to an interesting and educational workshop for local children during National Science Week 2002. Dr Colin Wright is a computer scientist working in industry who has a secret life as The Mad Juggler. Clutching

a bag of balls and clubs (but sadly no clown outfit), he tours the country using juggling as a way of explaining some of the complexities of mathematical pattern to young people in an engaging and amusing way.

PEALS promoted an evening with the Mad Juggler as our contribution to Science Week 2002: International Centre for Life provided the venue and One NorthEast covered the costs, as part of their support for Science Engineering and Technology education in the region. As well as showing us some entertaining tricks, Colin showed how it was possible to develop a simple mathematical notation for juggling. Having helped him classify the tricks he had first shown us, the audience were then able to work backwards from his notation to demand new and previously unthought-of tricks, some of which Colin was even able to perform.

The audience was divided between eager young maths pupils and members of the region's circus skills fraternity, who disappeared with our guest after the presentation, no doubt to explore the mysteries of cascades, reverse cascades, mathematical notation and the world record for keeping balls in the air. We were left convinced that juggling has a part to play in helping today's younger generation understand that maths can be fun, as well as being a vital skill in their future careers and daily lives.

## Screening the Gene Conference

For the third year in a row, PEALS has supported a spring symposium on an aspect of biomedicine or bioethics. In 2002, PEALS collaborated with local voluntary agency Disability North and *The Guardian* on Screening the Gene. Intended for people in law and business as well as members of the public, this symposium brought together expert speakers to discuss discrimination in insurance and employment, arising out of access to genetic information. Feedback was extremely positive, and the presentations from the day have been made available via the PEALS website.

*Janet Schofield, who was lead organiser for the event, writes:*

On 28th February 2002, a historic conference took place in Newcastle's International Centre for Life with the intention of beginning a public debate on key issues relating to genetic testing in employment and the insurance industry. What protection would people have when turned down for a mortgage or job because a test indicates that although they don't have a condition at present they may get it in the future?

A range of authoritative speakers addressed delegates attending the event. Copies of presentations can be found at [www.peals.ncl.ac.uk/Screening/index.htm](http://www.peals.ncl.ac.uk/Screening/index.htm)

Extracts follow below.

Dr Ian Gibson, Labour MP for Norwich North opened the debate:

"Genetics has become a major issue in terms of our understanding of human health. Insurance companies and employers are, of course, interested in using it to determine whether people should have insurance policies and if they should be employed. The offer of a job

should not depend upon a person's DNA but on their skills to carry out that job. If there is a hazard in the workplace, the workers and those hazards should be separated using better technology or appropriate clothing, for example. The scientific process tells us nothing is black and white and that genes act together. It is very rare to find one gene causing a specific condition. We can never be 100 per cent sure - that's the nature of the beast. Employers and employees are getting excited about the new genetics without any justification that they can predict what illnesses people have and when. No one has perfect genes or DNA, and we must ensure science can't be manipulated by anyone for their own reasons. We cannot shy away from these questions."

Professor Alexander McCall Smith, vice chair of the UK's Human Genetics Commission (HGC), chairs the working group on personal genetic information and spoke about the role the HGC is playing in bringing discussions around human genetics into the public domain, for example the Whose Hands On Your Genes consultation. Caroline Gooding, special adviser to the Disability Rights Commission re-iterated the need for legal protection of individual's rights:

"We want to see a statutory framework to address these issues. This includes extending the Disability Discrimination Act to include people with a genetic predisposition who are not covered until they actually develop a condition and experience symptoms."

Professor Angus Clarke (University of Wales College of Medicine) said: "When it comes to employment there are potential attractions for employers thinking about genetic tests for the workforce. In extreme cases they can raise potential justifications for genetic testing, for instance, public safety if an airline pilot is at risk of Huntington's disease. They must be very careful about using such abstract scenarios to

justify gene policy when there might well be other ways around the problem. There is a limit to what genetics can predict."

Richard Walsh is head of health at the Association of British Insurers (ABI) and spoke from an insurance perspective:

"The five-year moratorium on genetic testing for insurance purposes began in October 2001. Insurers cannot ask for the results of genetic testing in the interim. The only genetic tests allowed, such as for Huntington's disease, are those approved by the government's genetic and insurance committee. They affect only a small number of people. Gene testing is a complex subject, with lots of different views. Everyone needs insurance. Therefore there must be a consensus for a future system that which allows people to buy insurance and ensures people with genetic impairments have a reasonable level of insurance."

Angus Macdonald, Director of Genetics and Insurance Research Centre stressed that currently, in the UK, access to insurance is about wealth - being able to afford policies. He felt that the question that should be raised is "Is insurance a right?" and if so, "Should people at risk pay more?"

The conference ended on a high note with a live video link up to the US and Paul Miller, a commissioner at the US Equal Employment Opportunity Commission:

"The US has stronger human rights than the UK. While there are currently no federal laws that directly regulate the gathering of genetic information in the workplace, the 1996 Health Insurance Portability and Accountability Act (HIPPA) prohibits the use of genetic information and prevents compulsory tests for insurance policies. In the workplace, we have the 1990 Disabilities Act and the 1973 Rehabilitation Act, which prohibit discrimination

based on disability, but neither explicitly refers to genetic information. In the 2001 state legislative sessions, there were more than 60 bills introduced regarding genetic discrimination in the workplace and/or genetic discrimination by insurers. In February 2002, senior Bush administration officials called on Congress to pass legislation to bar employment and insurance discrimination based on genetic information."

Screening the Gene was a successful event as it raised people's awareness of the issues surrounding genetic testing. We are standing on the brink of massive medical developments that will aid humanity - or are we? The implication for disabled people is that after years of work to eliminate unfair treatment and discrimination, this technology may be used to discriminate against them and people who may be disabled in the future. The problem with genetic screening is that science is progressing a lot faster than the legislation and there is going to be a time where people aren't protected by the law. As science progresses, more and more things that can be tested for will be found. There are also moral and ethical issues for the whole of society to consider... watch this space.

*Janet Schofield  
Disability North*

## **Gamete Donor Information Consultation**

One of the clinical options available to infertile couples is to use donated sperm or eggs in order to try and create a baby. This raises social and ethical dilemmas: what rights do children created using this method have to find out the identity of their 'biological parent' - in other words, the individual who has donated the sperm or egg? Equally, what rights do egg and sperm donors have to anonymity and privacy about their donation? There is

currently a legal right to discover that one has been born as a result of such a procedure, but identifying information about gamete donors is not retained or available. However, for many years adopted children have had the right to have information that might allow them to trace their birth parents, and many individuals have chosen to do so. There is a strong argument that this option should be available to children born as a result of gamete donation.

In 2002, the Department of Health issued a consultation document about whether in future identifying information should be collected and made available to those who request it. However, there are some practical and ethical problems with the proposal. Many people only donate gametes on the basis that they cannot be subsequently identified. If one man has donated sperm that has led to the conception of many children, it might be very difficult if they subsequently make contact with him. Such a father's own family might find it difficult to embrace new 'siblings' or 'step children'.

PEALS held a public meeting about the issues raised in the Department of Health consultation at the Literary and Philosophical Society, Newcastle-upon-Tyne, on 12th June 2002. Speakers included Professor Eric Blyth (University of Huddersfield Department of Social Work), Professor Erica Haines and Dr Alison Murdoch (Head of Reproductive Medicine,

Newcastle Hospitals NHS Trust). A range of individuals from the region with a personal or professional interest in the issues gathered to hear the arguments and debate with our speakers.

## **Science Fact and Science Fiction**

At the end of her Royal Literary Fund writer in residency, Carol Clewlow developed several innovative pieces of work. One was a collaboration with Newcastle Cathedral, which we hope will result in a publication during 2003. Another was her partnership with other writers and doctors in the Operating Theatre project, which has now become an independent programme. A third was a group of writers and scientists called The Science Fact and Science Fiction club, which met for two engaging evenings at the Literary and Philosophical Society. Designed to explore common themes and experiences in writing about science, or drawing upon science, in different genres, the wine and conversation flowed freely. At the first meeting, Professor Milan Jaros, Newcastle's polymathic theoretical physicist cum philosopher, debated with Andrew Crumey, local novelist and literary journalist. At the second, our own Dr Tom Wakeford, biologist and science communicator, debated with Chaz Brenchley, another stalwart of the local literary scene best known for his horror and fantasy novels. We hope to revive and continue the format in years to come.

## Using creative writing in science and medicine

A report from writer in residence Lisa Matthews:



The innovative idea of having a writer in residence came to fruition in September 2000 when Carol Clewlow began the first half of a three-year programme, funded by the Royal Literary Fund. Eighteen months later in March 2002 I took over and it has been a whirlwind of activity. Building on Carol's work and utilising her network of contacts, I have been able to take the genetics debate even further out into the community.

At least half of my brief for this job seems easy enough if you say it quickly: I've to use creative writing to allow people to explore their hopes and fears surrounding the new genetics and I've to utilise literature and the arts to help doctors hone their communication skills - I'll let you decide exactly which half of that brief is easy. However, like most of the people I come into contact with at workshops, I experience genetics as a confused consumer of newsprint and feel the sharp end of the NHS as a

semi-informed patient. This gives me an objective edge and allows me to examine my own hopes and fears along with the workshop participants: it also means this residency is far from a walk-in-the-park.

Since March I've worked with: children in museums looking at progress and innovation; with adults who've never written creatively before in their lives; with young people in communities where writers rarely tread, and I rode high on the summer Spiderman explosion to look at the notion of genetically modified human beings with younger children.

No one is born with knowledge. We come into the world empty vessels; we're filled-full by our parents and guardians, siblings, friends and peers, by economics and politics. Bearing this in mind, I've encountered staggering eloquence and insight along the way.

When I took this job I believed, absolutely, that everyone has an opinion on genetics. My opinion has not changed. No one can fail to be moved by stem cell research, genetic testing, GM food and cloning - not to mention the attendant media hysteria.

And what of the trainee doctors? They view me, I think, with a healthy scepticism and it is heartening that our medical schools are committed to the integration of Medical Humanities into the curriculum. Asking a medical student to look creatively at the metaphorical language of pain ("Doctor, it's like a knife") is a sensible thing to do. It's not our intention to change them into writers; rather we are encouraging them to see language as a tool at their disposal.

This autumn I've been working with women's groups, writing groups of older people and I visited, among others, the Women and Girls' Centre in Elswick to do some work with a group of teenage girls. These teenagers were sharp as tacks and twice as witty, they engaged fully with the debates and did some great and

insightful presentation work. Maybe they'll have me back for a return visit. Who knows? I've also been hot-footing it down to the Stockton Campus of Durham University to do some work with the medical students. The Stockton Campus is built on a piece of land where Mrs Thatcher was famously photographed considering the desolation while wearing a yellow hard hat. It's nice to know that after over a decade of laissez-faire, I'm-alright-jack policies, the general public are still keen to be involved in community work and make their voices heard.

Genetics may be a precise science, but its consequences are very human. That's the message I take wherever I go. I need to be able to deliver this concept in a variety of registers and before I can even try to get people writing we have to do some work unpacking the scientific concepts. I love the challenge of finding new ways to make complex ideas accessible subjects for debate. Great work for a jobbing writer. It's inspiring, challenging, sometimes scary but always satisfying.



## **Genius Gene**

(an acrostic poem)

**G**enius genes  
**E**veryone is intelligent  
**N**o one can fail  
**I**diots are now non-existent and there is  
**U**niversal understanding of all things, what a  
**S**uper invention - the genius gene.

*Amy, aged 13*

## **Perfect**

The world is made of wood  
Its god sifts sun  
in shavings on the floor  
heats air distilling scents  
cedar  
that tastes of cinnamon  
ash  
that tastes of olive  
oak  
that tastes of gall  
And on that air  
are woodwind leaves  
flute music  
Always and  
everywhere.

*C.E. McCulloch, 60+*

## **What would *you* do to help?**

GM food - maybe it will cause more mad-cow-diseases?  
Cloned food - could we send it to starving children?  
If you're starving - what choice do you have?  
Do you accept - or do you refuse?  
Do we understand enough to go ahead?  
What about our environment?  
Should we ask the government, or the UN?  
What if we can grow food quicker?  
What if the food were safe for consumption?  
What if we could solve famine and hunger?  
What if the plants were resistant to bugs?  
Lucky plants, but what about the bugs?  
If you or your child was hungry  
Would you eat GM food?

*Collective composition/presentation by the West End Girls Group, Elswick*

## Memory and Forgetting

The REPRO project in 2001 brought together the Northern Print Studio, the Hatton Gallery and PEALS to create an exhibition that attracted thousands of visitors. Four young artists from the region created work inspired by genetics and reproductive technology, and worked in schools to enable young people to engage with the science. The project showed the potential for this type of sci-art initiative, and the three partners were very keen to build on success and take the idea further. The result was a new bid to the national Sci-Art Consortium for a project called Memory and Forgetting.

We were inspired by the exciting new work in psychology and neuroscience, charting the complexities of brain function, and trying to conceptualise the processes of consciousness. The concept of memory is a rich field for research, but the subject is also attractive to artists in many disciplines. We felt there was an opportunity to bring together people from both sides of the sci-art divide and to see how each could inspire the other.

We were successful in getting a grant from the Consortium and another from the Northern Arts Board to fund a research phase for a future exhibition.

We recruited the following artist/scientist pairs:

Daniel Sturgis Dr Anya Hurlbert	painter physiologist, Newcastle University, exploring colour memory and perception.
Louise K. Wilson Dr Madeleine Eacott	installation/performance artist psychologist, University of Durham, exploring childhood amnesia and the research process.
Shona Illingworth Prof. Martin Conway	video/sound/installation artist psychologist, University of Durham, exploring autobiographical memory.
Ashley McCormick Dr Julian Hughes	multi-media artist consultant psychiatrist, Newcastle General Hospital, exploring Alzheimer's disease and collective and individual identity.

The collaboration has been marked by openness, generosity and enthusiasm on both sides. Visits to the region, meetings with patients, viewings of exhibitions, time at Northern Print Studio, and a steep learning curve on both sides have created exciting ideas for the exhibition, to be held between March and May 2003. A sci-art symposium in September 2002 marked the end of the first

stage of the collaboration: members of each pairing presented their work and their future plans, and an audience of scientists, artists and critics discussed the ideas involved. We were delighted to welcome curators Marina Wallace and Caterina Albano, as well as colleague Professor Gollinelli, who contributed helpful feedback.

After the end of the period covered by this report, we learned that we had been successful with our subsequent funding applications to complete the production and exhibition stage of the project, and a full record of the work will be included in next year's annual report.

## Science as culture

From the outset, PEALS has been committed to sci-art and to arts in health. We believe that the arts have an important role to playing in fostering debate on science and medicine, and enabling communication between professionals and the public. Many of the values that motivate artists - such as creativity, imagination, wonder, empathy, curiosity and even fear - also motivate scientific researchers. The same spirit of innovation and excellence should be at the heart of good science and good art. Both science and art can be elitist and inaccessible. Yet art and science are cornerstones of national culture, and fostering a conversation about both domains is an important part of the PEALS mission.

We were therefore delighted to contribute our experiences to a range of cultural meetings this year. The Two Cultures Conference in Bradford was the forum for workshops and debates on many aspects of the science/art divide (or

increasingly, continuum). The Association of Local Authority Arts Officers meeting in Newcastle was another opportunity to showcase the PEALS achievement and spread the word about science engagement as an opportunity for art. Throughout the year, PEALS contributed to debates around the Newcastle-Gateshead European City of Culture bid 2008. We are determined that science should be a part of the broad vision of culture envisioned by the team at the Newcastle-Gateshead Initiative, and we felt it was important to fly the flag for the region wherever possible when we travelled abroad.

Closer to home, we were able to use our experience of the REPRO and Memory and Forgetting projects, and our close contact with many of the region's scientists, to support the Northern Arts/Wellcome Trust initiative to create new performing arts work for young people on biomedical and bioethical themes. We held a seminar at Northern Arts where scientists and medics presented their research to a fascinated audience drawn from the region's major performing arts companies. Applications have subsequently been developed by artists, many of them informed by information and advice offered by PEALS, and we look forward to some innovative work being produced in 2008.



# FUTURE PLANS

Our priority is to expand our research activity. This will include major enterprises, such as the University of Newcastle's bid to establish a highly prestigious £2.5m ESRC-funded international Genomics Research Forum, led by Erica Haines, and our participation in two UK Biobank bids - one for a 'hub', led by Alastair Balls, and one for a 'spoke', through a Newcastle-Durham-Leeds consortium.

It also includes a range of project bids. Erica Haines and Dr Alison Murdoch (Reproductive Medicine) are applying for Wellcome Trust funding to study potential donors' views on donation of embryos for pre-implantation genetic diagnosis (PGD) and embryonic stem cell research. They are also co-applicants with other colleagues to the Medical Research Council's "Targeted call for expression of interest in developing consortia that foster two way collaborations between IVF clinics and researchers in the context of the national stem cell initiative".

Tom Shakespeare is collaborating with geneticist Dr Michael Wright on a Community Fund bid to explore quality of life in skeletal dysplasia. With Professor John Carpenter (Durham), Professor Kate Bushby (Newcastle) and colleagues, he is also bidding for funding to explore the experience of young adults with Duchenne muscular dystrophy.

PEALS will also be contributing its sociological and ethical expertise to consortia bidding for European Sixth Framework funding on haemopoietic stem cell and on gerontology research.

New PhD students add another element to the PEALS team. Lorraine Summerville has won

ESRC funding for her research on ageing. Pam Chapman will combine her experience as a genetics nurse specialist and highly experienced researcher to explore young people's experiences of familial colon cancer. Stephen Macdonald is beginning research on social identity in dyslexia. In addition, Rachel Lowenson, a part-time PhD, continues her work studying issues of paternity testing in the Child Support Agency.

On the outreach front, we continue to work to promote citizen participation. In August 2002, PEALS won a competitive tendering process to undertake a joint research programme with the Royal Society's Science in Society Programme. This involves a series of regional "Speaking Out" meetings in Edinburgh, Leeds, Newcastle and Norwich, culminating in a "People and Science Summit" in London during March 2003. Further details from: [www.royalsoc.ac.uk](http://www.royalsoc.ac.uk)

Developing multi-media capacity is a new outreach priority. Following production of web resources for the British Council and a bioethics video for ICFL in 2001-2, we will be starting work on the Antenatal Screening Web Resource (AnSWeR) in 2003. This is a Wellcome Trust-funded project to provide balanced information about conditions for which pregnant testing and termination are offered.

In March 2003, our new Director of Learning, Dr Simon Woods, joins us from Manchester. With a PhD in philosophy and a background in palliative care nursing, Simon will lead on our Masters and Continuing Professional Development programmes, as well as adding another dimension to our research and outreach activity.

# Appendix One:

## PEALS Events during 2001-2

### 2001

**4th October:** Frontiers of Science: mouse genetics, public meeting with Professors Alan Holland and John Burn.

**10th October:** research seminar with Dr David Porteous, University of Edinburgh, "The maddening hunt for genes in health and illness".

**11th October:** Science Fact and Fiction Club with Milan Jaros and Andrew Crumey

**15th October:** café scientifique with Professor Igor Aleksander, Imperial College, "Machine Minds: What do they tell us about real ones?"

**19th November:** café scientifique with Professor Michael Akam, Cambridge University Museum of Zoology, "Why is a mouse not an elephant: The genetics of animal diversity".

**13th December:** Science Fact and Fiction Club with Tom Wakeford and Chaz Brenchley

### 2002

**21st January:** café scientifique with Dr Tom Wakeford, "Liaisons of life: the symbiotic revolution".

**30th January:** research seminar with Professor Jerome Bickenbach, Queen's University Ontario. "Genetic Screening and Children: Pre-empting Quality of Life" examining bioethical arguments about both prenatal and infant screening.

**11th February:** research seminar with Sarah Parry, Science Studies Unit, University of Edinburgh, "Public understanding of stem cell research: cloning, embryos and life".

**18th February:** café scientifique with Professor Lawrence Whalley, University of Aberdeen, "Can nutrition solve the problems of brain ageing?"

**28th February:** conference, "Screening the Gene"

**4th March:** research seminar with Caroline Bowditch, Genetic Support Network of Victoria, "The role of genetic support groups in the work of a clinical genetics service".

**11th March:** workshop, "The Mad Juggler"; Dr Colin Wright.

**18th March:** research seminar with Dr Anne Kerr, Science and Technology Studies Unit, University of York, "Towards a social history of cystic fibrosis: disease, professions and policy."

**25th March:** café scientifique with Professor Chris McManus, University College London, "Human right handedness and the left handed neutrino: Is there a link?"

**22nd April:** research seminar with Simo Vehmas, University of Turku, Finland, "Toward an ethical model of disability?"

**8th May:** research seminar with Alex Howard, "Philosophy outside the Academy: Finding the philosopher in each of us."

**20th May:** café scientifique with Helen Wallace, GeneWatch, "Selling promises, ignoring causes: the role of genetics in health prevention".

**29th May:** research seminar with Dr Robert Song, Durham, "What can theology offer genetics?"

**8th June:** open sessions for "Philosophy for Children" facilitated by James Nottingham.

**12th June:** public consultation on gamete donor selection.

**17th June:** café scientifique with Professor Hilary Rose, Bradford and Greshams College, "Learning from the Icelandic genetic saga?"

**15th July:** café scientifique with Professor Peter Olive, Newcastle, "Oh, I do like to be beside the seaside!"

**16th September:** café scientifique with Professor John Dupre, Exeter, "Beyond human genetics".

**18th September:** research seminar with Professor Alan Peterson, University of Plymouth: "Managing a genetic condition: the dilemmas of choice".

## Appendix Two: New external funding secured during 2001-2002

Memory and Forgetting	Northern Arts	3,000
Memory and Forgetting	NESTA	5,000
Memory and Forgetting	Arts Council of England	5,000
The Mad Juggler	ONE NorthEast SET funds	375
Janna Levin Café Scientifique	Institute of Physics	250
DNA 50 web portal research	British Council	1,440
Ordinary Ethics	Wellcome Trust	75,997
Director of Learning	Northern Genetics Knowledge Park (Department of Health/DTI)	292,345
Peals core funding (2002-7)	Northern Genetics Knowledge Park (Department of Health/DTI)	50,000
Peals core funding (2001-3)	University of Newcastle Faculty of Humanities, Arts and Social Sciences	10,000
Peals core funding (2001-3)	University of Newcastle Faculty of Medicine	10,000
<b>Total funding secured</b>		<b>453,407</b>

# Appendix Three:

## PEALS participants' relevant research and policy outputs 2001-2002

**Dr Sarah Banks (Community and Youth Work Studies Unit, Department of Sociology & Social Policy, University of Durham)**

Durham Rural Community Council (Executive Committee)

Steering Committee for project to develop training for Community Practice

European Social Ethics Project (Co-ordinator)

### **Publications**

Ethics and Values in Social work, 2nd edition, Palgrave: London, 2001

[with Paul Burlison and Tom Shakespeare] Youth work and biomedicine: an exploratory study, Youth and Policy, No. 74, Winter 2001/2, 18-39

Professional values and accountabilities in R. Adams et al. (eds) Critical Practice in Social Work, Palgrave: Basingstoke, 2002, 28-37

Becoming confident: ethical challenges for European social education students in S. Elsen, G. Friesenhahn and W. Lorenz (eds) Für ein soziales Europa Ausbilden - Lernen - handeln in den sozialen Professionen, Schriftenreihe des Pädagogischen Instituts der Johannes Gutenberg-Universität, Mainz, Germany, 2002.

**Professor John Burn (Department of Human Genetics, University of Newcastle University)**

Member of Human Genetics Commission - post renewed for a second term.

Invited to join the Steering Group of the Bioscience Innovation and Growth Team at the DTI.

Member of the Advisory Committee on the forthcoming Green Paper on Genetics.

### **Presentations**

"Society and Genetics", Newcastle Literary and Philosophical Society.

Plenary Speaker at the German Society of Human Genetics.

Guest of the Icelandic Medical Association, speaking on complex genetic trait analysis.

Lecture tour of South Africa, supported by the South African Association of Obstetrics and Gynaecology, including presentations in Pretoria and Cape Town on the ethical aspects of prenatal diagnosis and future technical developments in the field of prenatal genetic testing.

Scientific adviser to the BBC2 series 'How to Build a Human' broadcast in the UK at the beginning of 2002 and since internationally, including Australia.

Contributed to the promotional video, which formed part of the successful application by Newcastle and Gateshead to be shortlisted for the City of Culture Bid 2008.

## **Professor Erica Haines (Department of Sociology, University of Newcastle)**

Wellcome Trust-nominated international referee for Swedish national ELSA (Ethical, Legal and Social Aspects of Genetics) Research programme, 2000-to date

Management Committee, Northern Genetics Knowledge Park

Invited to be founding member of Editorial Board, "The New Review of Bioethics" (March 2002)

Research development meetings with colleagues in the Centre for Medicine, Ethics and Law; Applied Bioethics; Epidemiology and Biostatistics, all at McGill University, Montreal and with colleagues in the Centre for Research in Public Law and in Genetics and Society, both at the Université de Montreal (September 2002).

ESRC PhD studentship on 'Ordinary Ageing' with Lorraine Summerville

Appointed to the UK Biobank Interim Advisory Group (Ethics and Governance) by the Wellcome Trust, the Medical Research Council and the Department of Health

### **Publications**

What can Sociology contribute to the study of ethics? Theoretical, empirical and substantive considerations, *Bioethics*, 16 (2), 2002, 89-113

The provision of donor insemination for lesbian couples: research evidence and implications in Healy, D. (ed) *Reproductive Medicine in the Twenty-first Century*, Parthenon Publishing: London, 2002, 86-96 (IFFS World Congress Plenary papers)

When transgressions become transparent: limiting family forms in assisted conception, *Journal of Law and Medicine*, 9(4), 2002, 438-448

### **Presentations**

PEALS briefing, House of Lords Select Committee on Stem Cell Research

Invited plenary speaker, International Federation of Fertility Societies World Congress. Melbourne, Nov 2001

Invited plenary speaker, Satellite Symposium, 'The welfare of the child in new family formations', IFFS World Congress (as above)

Invited plenary speaker, Satellite Symposium, 'Donor linking in assisted conception', IFFS World Congress (as above)

Invited plenary speaker, National Study Day on Genetic Databases, University of Bristol, January 2002

Led PEALS contribution to 'GovGen' (Governance in Genomics and Genetics), a submission to the European Commission Sixth Framework Programme on Genomics and Biotechnology, led by Centre for Global Ethics, University of Birmingham (May 2002)

Public meeting, Newcastle upon Tyne, to discuss the public consultation document on identifying semen donors (June 2002)

Wellcome Trust-invited panel member, European Association of Social Studies of Technology Annual Conference, York, August 2002

Invited participant. European Association of Social Anthropologists Annual Conference, Copenhagen, August 2002

Paper presented at the 'Hopes and Fears! The Future for Health' International Policy Futures Conference, Cambridge University (presented by Michael Whong-Barr) September 2002

Selected plenary speaker, Third International DNA Sampling Conference, Montreal, September 2002

### **Professor Tom Kirkwood (Institute of Ageing and Health)**

See full report at [www.ncl.ac.uk/gerontology](http://www.ncl.ac.uk/gerontology)

### **Dr Tom Shakespeare (Department of Sociology, University of Newcastle)**

Membership of the Nuffield Council on Bioethics Working Party on Genes and Behaviour

Membership of the Newcastle NHS Hospitals Trust Clinical Ethics Advisory Group

### **Publications**

[with S.Banks and P.Burlison] Youthwork and biomedicine, *Youth and Policy* 74, 18-39

[editor, with M.Corker] *Disability/Postmodernity: embodying disability theory*, Continuum: London.

[with A.Kerr] *Genetic Politics: from eugenics to genome*, New Clarion Press: Cheltenham, 2002

### **Presentations**

Talk to Soroptimists International of Durham, October 2001

Keynote lecture to British Association of Occupational Therapists Northern and Yorkshire Region Study Day, October 2001

Paper presented at Glaxo Smith Kline Foundation Symposium on Predictive Medicine, Munich, October 2001

Ethics of Stem Cell Research: presentation to Medical Ethics in Gerontology Group, November 2001

Presentation at Making Biotechnology Happen 2002 Conference, ICFL, January 2002.

Talk to Tyneside Kidney Patients Association, Newcastle, January 2002

Talk at St Thomas More Secondary School, Blaydon, February 2002

Talk at Common Purpose regional health day, Newcastle, February 2002

Expert contribution, BBC/Wellcome Trust Open House on Genetics, ICFL, 2002.

Keynote speaker, European Congress on People with Disabilities, Madrid, March 2002.

Keynote speaker, 3rd Regional Forum for Music in Special Schools, Sunderland, March 2002

Keynote speech, Children's Foundation Annual Review and AGM, Newcastle, March 2002

Lecture on Marc Quinn genomic portrait of Sir John Sulston, Hatton Gallery Newcastle, April 2002

Presentation on pre-implantation genetic diagnosis to National Council of Women Study Day, Sevenoaks, April 2002

Talk at National Association of Local Government Arts Officers on 'Science as culture', May 2002  
Public Meeting on Genetics, Melbourne Town Hall, Australia, May 2002  
Schools workshops on genetics, Melbourne Museum, Australia, May 2002  
Seminar on disability, Deakin University Geelong Campus, May 2002  
Research Seminar at Department of Genetics, State University of Firenze, June 2002  
Talk at Common Purpose All Staff Day on Democratising Science, June 2002  
Talk at end of year celebration for University of Durham Stockton Phase One medical students on 'Medicalization and its discontents', June 2002  
Keynote speaker, Nordic Network of Disability Research Annual Conference, Reykjavik, August 2002  
Keynote lecture to Heads of University Courses in Biomedical Science annual conference, ICFL, September 2002

Genetics talk to Whitley Bay University of Third Age, September 2002

**Dr Robert Song (Department of Theology, University of Durham)**

**Publications**

Human Genetics: Fabricating the Future, Darton, Longman and Todd: London, and Pilgrim Press: Cleveland, Ohio, 2002

**Presentations**

November House of Lords Select Committee on Stem Cell Research: the status of the embryo.  
St John's College, Durham

**Revd Bryan Vernon (Department of Primary Care, University of Newcastle Medical School)**

**Publications**

[with L Ward] Teaching Medical Students to make mistakes better: the Newcastle experience, Canadian Bioethics Society Conference, Winnipeg, 2001.

**Dr Tom Wakeford (Department of Sociology, University of Newcastle and Institute of Development Studies, University of Sussex)**

**Publications**

[with F Hale] *The Future of Food and Farming: A Report on the Weekend Away for a Bigger Voice Workshops for the National Consumer Council*, 2001.

Bringing Science Down to Earth, *Science and Public Affairs* October 2001.

[with F Hale] Going Beyond "Consultation" *Local Government Briefing* November 2001

[with M P Pimbert] 2001. Deliberative democracy and citizen empowerment. Special issue of PLA Notes 40, IIED. Co-published by The Commonwealth Foundation, ActionAid, DFID, Sida and IIED, 2001. Downloadable from: [www.iied.org](http://www.iied.org)

[with M P Pimbert] *Prajateerpu- A Citizens Jury/Scenario Workshop on Food and Farming Futures in Andhra Pradesh, India*, International Institute for Environment and Development, London, 2002. Downloadable from: [www.iied.org/pdf/Prajateerpu.pdf](http://www.iied.org/pdf/Prajateerpu.pdf)

Citizens Juries: a radical alternative for social research, *Social Research Update* 37, 2002  
[www.soc.surrey.ac.uk/sru/SRU37.html](http://www.soc.surrey.ac.uk/sru/SRU37.html)

Social scientists and the cult of the 'lay' person *Science and Public Affairs* April 2002.

Trying the cereal killers: Citizens juries and GM crops, *Earth Matters*, September 2002.

*Liaisons of Life*, Wiley, New York: 2002

### **Presentations**

*Steps Towards a Citizen Science*, British Council "Science Update Workshop", Guildford, Surrey, October 2001

Writing *Liaisons of Life*. Fact and Fiction Workshop, Newcastle, December 2001

*Evaluation participative des biotechnologies*, (with Dr Carine Pionetti), Keynote address at French Food Standards and Environment Agency (AFSSA). Paris, France, December 2001

*Are Microbes Evolution's Missing Link?* Café Scientifique, Newcastle, February 2002

Ecological Darwinism: Evolution Beyond the Gene. Studium Generale Lecture, Wageningen University, June 2002.

*Liaisons of Life: Is DNA a triple helix?* Genetics Department Seminar, Wageningen University, June 2002.

