

PEALS ANNUAL REVIEW 2003 - 2004



foreword

by Professor Erica Haimes
Executive Director

This review marks the fifth anniversary of PEALS. When we began in October 1999, backed by the universities of Newcastle and Durham and the International Centre for Life, we comprised Tom Shakespeare as the only full-time member of staff, and myself, juggling responsibilities in PEALS with full-time teaching commitments. Today, we comprise a core group of six staff, 11 other research staff and students based at our Newcastle site, and an active network of over 40 colleagues from across the two universities involved in research, teaching and public engagement events. We are an integral part of the Life Genetics Knowledge Park and we make important contributions to the wide range of activities that take place in the International Centre for Life. We have a vibrant regional network of researchers, practitioners, and diverse publics. We contribute to national and international policy, education and research. The “PEALS model”, our trademark integration of research, public engagement and teaching, is now firmly established and widely admired.



Professor Erica Haimes.

Details of the work that lies behind this success story can be found in this review and on our newly revised website (www.peals.ncl.ac.uk). Here I should simply like to express gratitude for all the support that we have received from funders, particularly the William Leech Trust, the Northern Rock Foundation and the Life Knowledge Park in the region, and the Wellcome Trust nationally. We are also pleased to acknowledge the support, participation and feedback of academic and clinical colleagues and members of the public who have taken part in our events and projects. Our challenge now is to sustain this pattern of success, to consolidate our achievements and to expand our activities into other areas of science, to meet our goal of ensuring that the social and ethical aspects of developments in the life sciences are rigorously investigated and debated.

The PEALS model depends on close working links with those involved in, and affected by, scientific research. Recent developments in Newcastle University's work on embryonic stem cell research have thus been both exciting and challenging for us. We are emphatic that our role is not to take any moral or political stance but to ensure that full dialogue occurs between different positions in these debates on the risks and benefits of stem cell research. For us, questions raised about this work go beyond technical problems and the moral status of the embryo, and include wider issues such as the opportunity costs of investing in this work and the quality of the claims about the eventual benefits. So, for example we have worked closely with the Newcastle stem cell team and we have begun a three year research project (funded independently by the Wellcome Trust)

with those who donate their embryos, without whom the science could not proceed. We have also participated in a number of public and professional meetings addressing social and ethical issues. We are rigorous in our interrogation of all views and committed to the principle of open debate.

Institutionally, we are now housed within two newly launched research organisations, the Institute of Policy and Practice at Newcastle University and the Wolfson Research Institute at Durham University. They provide PEALS with a network of “critical friends” of internationally respected calibre and a strong support infrastructure, both of which are vital to the success of any research group.

Looking at how far we have travelled over five years, and the particular progress over 2003-4, it is clear that there is a need and demand for our work, and that we have had many successes. With the support of our friends and colleagues, we hope to achieve even more over the next five years.



Professor Ray Hudson, Director, Wolfson Research Institute.



Professor Andrew Gillespie, Director, Institute of Policy & Practice.

We continue to run a lively and varied research programme in PEALS. In this section we highlight results from a recently completed project on “ordinary ethics” and report progress on a number of ongoing projects. The PEALS research strategy has two main elements. The first is targeting work that builds on our established areas of expertise in genetic and reproductive technologies and in disability studies, and on our growing areas of collaboration in ageing and in nanotechnology. The second is to be responsive to new opportunities. The work reported here on the National DNA database is an example of the latter in that it extends our involvement in research beyond the clinical domain into other major areas of the application of the life sciences, in this case criminal investigations. Both approaches continue to produce the high quality, interdisciplinary work that is our trademark.

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

Jackie Scully, Tom Shakespeare and Sarah Banks are in the final stages of this two-year Wellcome Trust-funded project. Our aim was to investigate the approaches and skills brought by lay people to making ethical evaluations in the new genetics. Looking at the topic of preimplantation genetic diagnosis (PGD) for sex selection, we held focus group discussions and one to one interviews with lay people and with clinicians for the purposes of contrast.

We have found that lay people (as well as the medical professionals we interviewed) are almost all opposed to prenatal sex selection. Many lay people use the idea that “children are a gift, not a commodity”. They are concerned that these kinds of choices risk turning children into a consumer item. More generally, people are ambivalent about the whole idea of extending personal choice. Whilst appreciating that increased choice gives some people more control over their lives, they feel that too much choice – particularly in the absence of useful information – is a burden. In the area

of reproduction, acceptance is a greater virtue than being able to choose. These opinions contrast with the more libertarian consensus found in the mainstream bioethics literature, though interestingly they share some features with feminist approaches to bioethics. Lay people drew on a range of arguments that could be identified as consequentialist, deontological and as a form of virtue ethics. As one respondent said:

“We're talking about moral choices, that there needs to be a clear debate about those things... it doesn't matter about your knowledge about science or your knowledge about whatever or whether you've got an MA or a PhD in whatever subject that it is, [...] it's about norms and values and those types of decisions should be made by a selection of people from all different types of groups within society because then you'll get a more equal, more diverse range of opinions.”



Sue Thompson.



Jackie Scully.



Sarah Banks.

Unlike philosophical bioethics, these arguments were less to do with working towards a logically consistent conclusion than with giving reasons for a strong moral intuition. These intuitions were not simply prejudice, but derived from personal experience or from relevant analogies. Working from our results, we will be suggesting ways in which these skills can be drawn on to foster genuine public engagement in bioethics. Please contact PEALS for a copy of the full report.

The restricted growth project

There is very little evidence, beyond the anecdotal, of the medical and healthcare experiences and social issues for adults with skeletal dysplasias. The Restricted Growth Project, funded by the Community Fund and in close collaboration with the Restricted Growth Association, began a three-year investigation in May 2003, and will seek to fill this gap. The project is unusual in that it will maintain a dual focus of medical/health aspects as well as life experience and quality of life issues, with particular focus on barriers to inclusion.

The team of Tom Shakespeare, Michael Wright and researcher Sue Thompson hope to include as high a proportion as possible of adults of short stature in the chosen geographical area of the North East, Cumbria and West Yorkshire; recruitment is already in progress. Questionnaires will provide quantitative data on health and social experience, and a 50% sample of respondents will also be interviewed in order to examine certain areas in greater depth and to include self-identified issues. Interviewees will also be asked to complete diaries for the 14 days following the interview to record significant events or thinking relevant to the project.

Publicity and dissemination of the findings will be an integral part of the project process. The project findings will assist the membership organisation and other interested parties in advocacy for barrier removal and more appropriate service provision for people affected by these conditions. In addition, it will also allow health care providers and other advisers to offer better information to families when a diagnosis of restricted growth is made.

Views on donating embryos for stem cell and other research

Research on this project is now well underway following the appointment of anthropologist Dr. Jacquelyne Luce in April 2004 to work with Erica Haimes. The initial period of the project involved familiarisation with clinical practices and an exploration of the various recent practical and rhetorical changes in the conceptualisation of embryo research. The second stage of this project, a year of intense fieldwork, has now commenced. This stage will include interviews with women and men who have been asked to donate embryos for research purposes, as well as interviews with those who did not use in vitro fertilisation technology to conceive. Ongoing analysis of emerging issues and close engagement with health professionals, policy makers and other scholars in the field are a priority of the project. To date, reflections on the ethical issues related to embryo research and potential implications for both embryo donors and non-donors have been presented at workshops, seminars, and international conferences.

For regular updates on the progress of this project, please visit the PEALS website.



Robin Williams.



Paul Johnson.



Tom Wakeford.



Genetic information and crime investigation

This project, led by our Durham Convenor, Robin Williams, and completed in May 2004, examined a large number of policy and operational documents produced by the Home Office and individual police forces. It also collected documentary material from a variety of other stakeholders including the Human Genetics Commission, the Information Commissioner and several organisations and groups who have an interest in the state collection and use of different kinds of genetic information. Robin and his researcher, Paul Johnson, carried out more than 60 semi-structured interviews with individuals from organisations directly involved in either using, or commenting upon the use of, DNA profiling in the criminal justice system – the police, forensic scientists, crime scene examiners, legal professionals, legislators, and those concerned with human rights issues. These various forms of data were used to provide a comprehensive ‘map’ of the legal, social and ethical issues relating to the use of DNA profiling and the National DNA database by the police.

Forensic DNA databasing: A European perspective

This new project, also conducted by Robin Williams and Paul Johnson, explores the scientific, technical, legislative and social contexts of the current growth of forensic databasing in support of criminal investigation in the states of the European Union. It considers the nature and implications of increased trans-national DNA data sharing and genetic information exchange as emerging trends in support of criminal investigations across the EU.

The research has five detailed objectives:

- To chart the differing policy contexts for forensic practices which exist throughout the European Union and the role of various key state and commercial organisations in the UK who are involved in the expansion and delivery of DNA technology for the purposes of the Europeanization of forensic databasing;
- To gather the views of a range of government, criminal justice, police and human rights professionals concerning the current, and possible expansion, of sharing and transferring genetic material across criminal jurisdictions and the ethical, legal and social issues which this raises, as well as the future legislative provision which trans-national database searching may require;
- To explore the current use of, and the future plans for, genetic analysis to predict “commonplace characteristics” of individuals in the UK and to assess the potential both here and abroad, for its introduction into routine crime investigation;
- To compare the UK response to ethical considerations, such as privacy, consent and confidentiality, with other European countries and to assess the existence of state driven legislation in Europe which protects individual rights in relation to genetic data;
- To examine the role of expert advisory committees within emerging variations in the governance of forensic genetic databases and consider the vulnerabilities of such governance to emerging trends in transnational policing.

For more information on both these projects, go to Durham University’s website, www.dur.ac.uk/sociology.its/

Democratising technology

The great disparities in quality of life between the fully industrialised and less-industrialised countries are mirrored by a “technology divide”, analysed by Tom Wakeford in a report for the Intermediate Technology Development Group in 2004. The report has three aims: to describe recent attempts to increase public control over science and technology; to highlight some of the difficulties and trade-offs in such initiatives; and to suggest principles and pointers for future work. The report is available from www.itdg.org/docs/advocacy/democratising_technology_itdg.pdf

In brief, the report argues the following. The lack of access by millions of women and men to the most basic technologies and the resources needed to create sustainable livelihoods helps perpetuate poverty, disease and hunger. Those proposing greater investments in scientific research often claim that technology transfer and globalised free trade will close the technology divide, and equalise opportunities among countries. Yet decades of technology transfer policies have had little visible impact on the daily experience of these people. Just providing access to basic technologies is not enough. People also need control, both over the use of existing technologies and the development of new ones. The only way of ensuring that any technology will benefit people is to provide opportunities for them to participate in its development. Such processes should not only draw on their existing knowledge and practices, but also on their assessment of particular circumstances in which the technology might be used. The twentieth century has seen the establishment of democratically accountable systems of governance in many parts of the world, yet science and technology by and large escaped such mechanisms of accountability.

To ensure that environmental sustainability and equal rights for every individual are safeguarded it is essential to combine scientific and technological innovation with democratic processes that encourage the active participation of all groups in society, unrestricted by intellectual property systems. Recent editorials in influential scientific journals and initiatives by senior figures in the scientific profession suggest that scientists are themselves ready for such an approach. As people and organisations search for solutions to challenges from global hunger and climate change to HIV/AIDS and urban pollution, the need for democratic accountability in scientific research and technological innovation is more urgent than ever.

Other research activities

As well as the above studies we are involved in a number of other projects as advisers, collaborators and consultants. Two EU Framework Programme 6 funded projects in which PEALS colleagues have had a central involvement were launched in 2004. PEALS’ involvement in the first, mentioned in last year’s report, on the Genetics of Healthy Ageing (GEHA), was central to securing the €8m total grant, as Erica Haimes designed the Ethics Work Package which is a requirement for all FP6 projects. She now chairs the Ethics Steering Group of this large, complex project. She also sits on the international Ethics Advisory Board of the second project, Nano2Life, which addresses the development of biological and clinical applications of nanotechnology. This involvement reflects PEALS’ growing participation in research on nanotechnology, an involvement that also reinforces our claim to be pivotal in research interests across the four main domains of clinical science, natural science, social science and the arts and humanities. More details will be available on all these projects as they progress, on the new PEALS website, in our termly newsletters and in next year’s review.

public engagement



Jury member questions a witness in Blackburn.



Ann Lackie.



Lisa Matthews.

Direct engagement with diverse audiences is a unique feature of PEALS. The breadth of our work is demonstrated by projects with two groups who have been neglected in science engagement: rural communities, and lesbian, gay and bisexual people. Meanwhile, we continue citizens' jury projects which achieve depth in participation.

Talking science in Cumbria

Dr Ann Lackie is now in the second year of her two-year "Talking Science in Cumbria" project, funded by the Wellcome Trust. Ann acts as a 'roving speaker', going out to community groups and schools in rural areas, to demonstrate the excitement as well as the ethical dilemmas of cutting-edge biomedical science. Between September 2003 and November 2004 she has run 40 events in places ranging from public bars to hotel drawing-rooms, and student common-rooms to village halls, talked to nearly 1100 people aged from seven years to more than 70; and driven more than 2400 miles in snow, fog, rain and sun to parts of Cumbria she never knew existed.

"There is a real need for presentations like this – so we can challenge and question from a more informed viewpoint"; "Fascinating, extremely informative"; "Very accessible to non-scientific mind"; "A good intro to a vital subject: I want to learn more"; "Made me think and cleared up many of my preconceived ideas/knowledge!"; "Spot on!"

The interest in the basic science, and the questions raised, show that the project has been worthwhile: more invitations to give talks arrive than can be accepted. Analysis of responses to evaluation questionnaires shows very clearly that attitudes toward genetics and biotechnology research shift towards the positive after the talks.

How gay are your genes?

This innovative project was launched in May 2004. Funded by the Royal Society, local writer and creative writing tutor Lisa Matthews hopes to consult and work with a variety of people from the lesbian, gay and bisexual (LGB) community. Together they aim to produce testimonies and visual artwork which will be exhibited at Newcastle's Hatton Gallery during 2006. The Centre for Life is in the geographical area of Newcastle's Gay Village, but the two communities – LGB and genetics – will be acknowledging each other for the first time through this project.

The first phase of the project is a round of public consultation and education. Lisa is visiting pre-existing LGB groups and giving an introduction to genetics, particularly focussing on behaviour genetics research and sexuality. One of the questions she asks is: if science were to discover genetic factors in sexuality, what would be the impact on LGB people? This raises strong emotions since science and sexuality is a hot topic: the original "gay gene" research, published in 1993, caused a media uproar. LGB people will be writing creatively about their views and working closely with people from all sides of the debate in the second phase of the project. The final artwork will celebrate and reflect the diversity of the LGB communities of the North East. This is challenging work, and is, as far as we know, the first science engagement project in the world to be aimed at the LGB community.

For more detailed information on the project, visit our website.

Developments in deliberative democracy

Top-down approaches to public engagement are regularly used by governments and other organisations, but suffer from a perception that they are merely being used to rubber-stamp decisions that have already been made. Bottom-up methods, such as DIY citizens' juries, are sometimes criticised for failing to engage with decision-makers sufficiently. Therefore a team of PEALS associates (Tom Wakeford, Bano Murtuja and Pete Bryant) have been experimenting, alongside community jurors in Blackburn, with a "convergent engagement" process which is aimed at connecting with the interests of policy-makers, whilst also giving people a say on issues that they choose. In the top-down strand, they took the theme of racial justice from the priorities expressed by their funder, the Joseph Rowntree Charitable Trust, as a key theme of a community jury process. In the bottom-up strand they undertook a DIY process that allowed jurors to prioritise an issue on which they felt it was important to have a voice.



Members of the Blackburn and Darwen Community Jury.

The Blackburn and Darwen Community Jury involved the researchers working with a "jury" picked at random from the local population who undertook a series of deliberative workshops during April and May 2004. The subject chosen by this do-it-yourself community jury at its first workshop was the rôle of the police in drink and drug use among young people. Having heard perspectives from a diverse set of "witnesses" the jury made recommendations, including:

- Changing social services rules to enable drug users to access rehabilitation schemes as soon as they stop using;
- The introduction of a tougher enforcement regime to target illegal sales of alcohol to under-18s;
- More community policing, with more ethnic minority police officers;
- New LEA-driven alcohol and drugs education programmes.

The jury at no point divided along ethnic lines. The whole jury were unanimous in their rejection of the tactics of far right groups in the North West, who they did not believe represented the public's interests.

From this work, we suggest that the re-building of democratic engagement in Northern England, as in many other parts of the UK, will be greatly enhanced by an increase of face-to-face meetings such as those that form the essence of a grassroots citizens' jury. Clearly, the convergent engagement process described here is applicable to a range of issues beyond community cohesion, and PEALS is now exploring how such approaches can be used in areas of development in the life sciences, such as nanotechnology. Such techniques go beyond the often rather cursory work normally associated with the phrase "public consultation".

teaching and learning

Simon Woods has continued to lead and develop the teaching and learning strategy at PEALS and this aspect of PEALS' work is gaining momentum.

Formal post-graduate education.

In the area of post-graduate education, PEALS' main aim is the recruitment of post-graduate research students and we are pleased to announce that Alex Henderson has recently joined us as a doctoral student, supervised by Simon Woods and Tom Shakespeare, with Kate Bushby, Professor of Neuromuscular Genetics. PEALS supported Alex's successful application for a Wellcome Trust short-term clinical fellowship which enabled him to engage in preparatory research to support his research application. Alex is a medical doctor and Specialist Registrar in Genetics, having also worked in paediatrics. Unusually for a clinician, he also has a Cambridge philosophy degree. This hybrid pedigree has influenced his research interests: he will be exploring the philosophical problems involved in paediatric research proposals using new genetic technologies. One outcome may be an ethical decision – making protocol for use by doctors and scientists in the preparation of similar trials.

We have also received enquiries from several possible candidates and are expecting further applications in 2005. We are of course interested to hear from anyone considering post-graduate study with PEALS. Please refer to our website for current projects and research interests or contact Simon Woods for an informal discussion.

The Institute of Human Genetics MSc in Human Genetics will soon be approved for a first intake in the autumn of 2005. PEALS will lead two of the taught modules exploring the ethical and social aspects of genetics and will be able to supervise dissertations related to these aspects.

Continuing Professional Development/Professional Training.

This has been an important area of development where our expertise and ability to deliver quality events has begun to be recognised locally and nationally. PEALS has developed a portfolio of teaching/training packages and is also able to offer bespoke short courses and training. Events over the past year include:

- Further commission from the Isle of Man Government (DHSS) to provide a training day for their Research Ethics Committee.
- Training days for the British Association of Counsellors and Psychotherapists (BACP) on the ethico-legal aspects of counselling practice.
- Series of Grand Round seminars at NHS Trusts within the Northeast: the format of these events is to facilitate discussion of common clinical ethical dilemmas such as resuscitation decisions, withholding and withdrawal of treatment, consent to treatment.
- Series of professional ethics seminars to the Newcastle Fertility Centre.
- Contributions to NHS Specialist Registrar training.
- Series of training events for members of Research Ethics Committees: including, law, ethics, genetics and qualitative research.



Alex Henderson.

PEALS and the Life Knowledge Park

PEALS is closely involved with the Life Knowledge Park (LKP), one of the six Genetic Knowledge Parks (GKPs) funded by the Department of Trade and Industry and Department of Health. In addition to conducting primary genetics research, the Parks promote research on the social and ethical implications of genetic research and encourage public engagement on the issues this research raises.

Liaison with other GKPs developed during the year. For example, PEALS is involved in the cross-GKP education and research ethics groups. The latter have been developing educational packages for researchers and members of Research Ethics Committees. PEALS, in conjunction with Newcastle colleagues, has designed and piloted the first of the training days for members of research ethics committees, delivered in York in September 2004. The day was very well received and there are plans to offer several further events in 2005.

PEALS collaborated with the North West Genetics Knowledge Park in June 2004 on a day-long workshop to explore "disability and reproductive choice". Speakers discussed the differing perspectives of disabled people and their families, parents experiencing antenatal diagnosis, and bioethics. The aim was to develop awareness and reflexivity among genetics and other healthcare professionals. A report is available from NOWGEN, and copies of presentations can be found at www.nowgen.org.uk



Simon Woods.

PEALS has also completed plans for a four-day continuing professional development course on "Genetics Knowledge and Practice." This course aims to provide knowledge appropriate to the core competencies of midwives but will also be relevant to nurses and health visitors. The course addresses the acknowledged gap between practitioners' current knowledge and what is considered to be the required level of knowledge of these health professionals. We will be advertising the course early in 2005 with the first intake planned for April.

2004 was also the mid-term evaluation point for the GKPs, who met with the DoH and DTI to discuss achievements to date and future plans. This meeting also doubled as a network event providing an opportunity for the GKPs to present ongoing work to each other, strengthen existing collaborations and discuss future work. PEALS facilitated a workshop on social science research and genetics, as well as making a strong contribution to the law and ethics workshop.

policy and practice

PEALS aims to use its expertise to improve professional practice and public policy in the life sciences. Different areas of our work contribute to this goal: production of research which can inform policy and practice; gathering and channelling of public views to regulators and policy-makers; service on public enquiries and ethics committees; training of professionals and policy-makers on social and ethical dimensions of their scientific or medical practice.

In May 2004, Erica Haimes was asked to contribute to a Nuffield Council on Bioethics workshop on “The way we reason: deliberations, consultation and policy in bioethics”. She addressed the question of “Public consultation or researching lay beliefs: what’s the difference?” and discussed the distinct but equally important contributions of consultations and of rigorous social science research to the policy making process in the life sciences. In July 2004 she was also appointed to the new Nuffield Working Party on the social, ethical, legal and clinical issues around the prolongation of life in fetuses and newborns. Improved clinical procedures and technologies are enabling more premature babies to survive, though often with severe impairments, so this eighteen-month investigation will explore the social and ethical complexities raised by these developments.

In March 2004, Erica contributed, with Professor Alison Murdoch, a keynote address to the annual conference of the British Fertility Society, exploring the ethics of embryonic stem cell research. In 2003-04, she also served as a member of the Interim Advisory Group on Ethics and Governance for UK Biobank, which established a practice framework which has been passed over to the new Ethics and Governance Council of this important MRC/Wellcome Trust-funded initiative to establish a national

genetic database. Erica also serves on the MRC International Advisory Committee on DNA Banking, which scrutinises the scientific, ethical, legal and social implications of the long-term storage of samples from research projects on a range of important clinical conditions.

Simon Woods and Tom Shakespeare both contribute to a range of NHS ethics committee deliberations in the region. Simon serves on the Newcastle Local Ethics Committee and, with Tom, contributes to the work of the Clinical Ethics Advisory Group of Newcastle NHS Hospitals Trust, as well as the Northern Genetics Service’s ethics journal club. Simon also contributes as an external member of the Northumbria University Research Ethics Committee.

Tom Shakespeare continues to work closely with the Disability Rights Commission, recently contributing to work on end of life issues and to the Human Genetics Commission, where he has contributed to the Choosing the Future consultation on antenatal testing. In September and October, Tom was invited to make submissions to the House of Commons Science and Technology Committee’s inquiry into Human Reproductive Technologies and the Law, and to the House of Lords Committee on the Assisted Suicide Bill, serving as a witness on both enquiries.

international links

From the start, PEALS has emphasised international connections and collaborations. Many of the social, ethical and legal issues raised by developments in the life sciences are shared across nations. But differing cultural contexts generate particular interpretations of these issues and lead to diverse responses. Our international contacts provide exposure to alternative approaches, opportunities for comparative projects and a wider audience for our research findings. Within the PEALS team itself, we have had colleagues from Canada, Germany, Greece, Switzerland and the USA, each contributing insights and connections.

This year, our involvement in the Genetics of Healthy Ageing and Nano2Life FP6 projects has extended our international links. They have revealed variations in European definitions of ethical issues, and in how such issues are “policed” by research ethics committees, funding bodies and professional guidelines. Often these differences arise unexpectedly in the everyday exchanges between researchers and are an important topic for research in their own right; we hope to develop this area in future.

PEALS was part of a major funding success in the USA, when colleagues at Case Western Reserve University, Ohio won a prestigious grant from the National Institute for Health to establish a Centre of Excellence for research into the social, ethical and legal issues raised by genetic technologies. We are a member of their international advisory board (singled out for particular praise by the funders) and will be participating fully in this research programme from early 2005.

International visitors included Dr Feruza Zagirtdinova, a TEMPUS fellow from Uzbekistan, from May to July 2004. Feruza spent her time with us investigating disability services and medical education in the UK. She also opened our eyes to the radically different context in post-Soviet, strongly Muslim Uzbekistan.



Dr Feruza Zagirtdinova.

Her work here will contribute to a book on biomedical ethics for Tashkent Medical Institution. We also welcomed visitors from the Université de Montreal, Dr Denise Avard and Dr Bryn Williams-Jones (who is now based at Cambridge University, UK). PEALS staff had previously attended a biobanks conference in Montreal hosted by Denise’s colleague Bartha Knoppers, who will be presenting at a British Council symposium hosted by PEALS in March 2005. Finally, we hosted a delegation from the Norwegian Foresight programme who were investigating UK Biobank and epidemiological research.

PEALS staff have been in demand as keynote speakers and conference presenters: this year we have contributed to events in Austria, Belgium, Brazil, Eire, France, Germany, India, Italy, Norway and Sweden.

events

Throughout the year, PEALS organises and hosts a range of events on science and ethics, where people from different backgrounds can debate issues of concern and explore ways forward. This year, we were glad to collaborate with the Centre for Life and other partners on the second Newcastle Science Festival: we contributed meetings on stem cell research; an address by Professor John Polkinghorne on “Genetics and the human person”; and a café scientifique by Dr Joao Magueijo on “Variable speed of light”, which was attended by 150 people.

Also in March we collaborated with Progress Educational Trust on a public event on “Saviour Siblings: is it right to create a tissue donor baby?” Scientists, sixth formers and members of the public debated with embryologist Simon Fishel, pro-lifer Josephine Quintavalle as well as our own Tom Shakespeare.

Each spring since 2000, we have held a symposium: this April, it took the form of the UK Forum on Health Care, Ethics and Law, which we organised together with the Newcastle Medical School’s Bryan Vernon. Social scientists and ethicists gathered to hear plenaries and give papers around the broad theme of “the future of healthcare”, and were entertained by North Tyneside Youth Theatre’s show, “Whose science is it anyway?”

In May, we hosted the second international gathering of the Café Scientifique network. The Wellcome Trust-funded conference brought together representatives of the two dozen other UK cafés, as well as colleagues from the French network, and from cafés in Argentina, Brazil, Denmark, Finland, Italy, Norway, Poland and the USA, to discuss further development of the network and the café scientifique model. Further information can be found at: www.cafescientifique.org

In September, two other events also focussed on antenatal screening. The first was the launch of the Antenatal Screening

Web Resource at the British Society of Human Genetics Conference in York. This Wellcome Trust-funded initiative provides testimonies from disabled people and their families: the site, which is currently being evaluated by colleagues at the University of Leeds, can be found at www.antenataltesting.info

The Human Genetics Commission ran a public consultation during the summer of 2004 on Reproductive Futures. As well as our own submissions, PEALS organised a well-attended public event in Newcastle to enable the public and professionals to hear different views and develop their own response. Further details of the consultation can be found at www.hgc.gov.uk



Tom Shakespeare at a British Council Event.

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