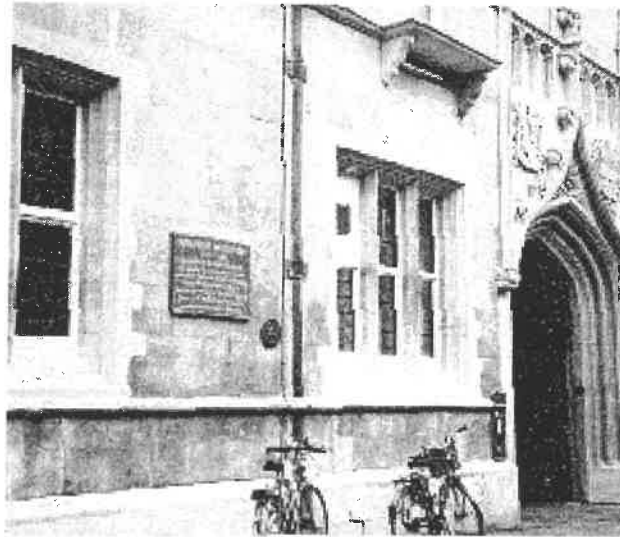




UNIVERSITY OF  
CAMBRIDGE



# CENTRE FOR FAMILY RESEARCH

Annual Report  
(Academic Year 2004-2005)

### **Support Staff**

Administrative Secretary	Jill Brown
Data Manager/Librarian	Sally Roberts
Cleaner	Anne Burling

### **Management Committee**

Chair: Professor Peter Lipton (Dept of History & Philosophy of Science)  
 Dr Mary Griffin (Secretary)  
 Dr Mavis Maclean (Centre for Family Law and Policy, University of Oxford)  
 Ms Maggie Ponder  
 Professor Martin Richards (Director)  
 Dr Jacqueline Scott (Social and Political Sciences Faculty)  
 Ms Helen Statham (Deputy Director)  
 Dr Darin Weinberg (Social and Political Sciences Faculty)

### **Joiners and Leavers**

During the year Professor Susan Golombok was appointed to be Director of the Centre and Professor of Family Research. She will take up the post in January 2006 following the retirement of Martin Richards at the end of December. Sally Roberts will be retiring in November 2005 and Jill Brown at the end of the year.

We welcome Zeynep Gürtin-Broadbent and Eric Jensen and Dr Charlotte Wilson to the Centre.

Dr Shobita Parthasarathy has been appointed to an Assistant Professorship at the Ford School of Public Policy at the University of Michigan and resigned her Wellcome Post-Doctoral Fellowship at the end of the academic year. Dr Bryn Williams-Jones position as a post-doctoral fellow at the Centre for Family Research ended during the year and he was appointed as a Fellow in Ethics at Cardiff University. He has since moved back to Canada to take up a post as Assistant Professor at the University of Montreal. Dr Chrissie Rogers' post-doctoral fellowship ended and Chrissie left to take up a lectureship at the University of Keele.

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## RESEARCH OF MEMBERS OF THE CENTRE

### Professor Martin Richards – Director

*Understanding inheritance and kinship connection (with Dr Anji Wilson). Funded by The Wellcome Trust. 2000 - 2005.*

This qualitative study describes everyday concepts of inheritance and analyses possible connection between this and concepts of kinship and family obligation. Qualitative interviews with samples of young people and recent parents were carried out and the data is being analysed and prepared for publication.

*Non-disclosure of genetic risk information (with Dr Angus Clarke, University of Cardiff and Lauren Kerzin-Storarr, N.W. Regional Genetics Service and other collaborators). 2000 - 2005.*

This multicentre audit study has collected data on the frequency and circumstances of non-disclosure to family members of significant genetic risk information following genetic counselling. It involves about 15 genetic centres in the UK and Australia. This project has now been completed and a paper published (see below).

*Psychosocial effects of molecular genetic diagnosis: the case of X-linked learning disability (with Nina Hallowell, Helen Statham and Lucy Raymond). Funded by The Wellcome Trust 2002-2006.*

This ongoing study examining family members' perceptions and experiences of an X-linked severe learning problem before and after the associated gene mutation has been identified (or not) using a high throughput mutation detection technique (the Genetics of Learning Disability Study). See Helen Statham's entry for further details.

*Informed consent and genetic data (Onora O'Neill, Patrick Bateson, Peter Lipton and Martin Richards). Funded by The Wellcome Trust 2002-2005.*

This project began in July 2002 and is based in the King's College Research Centre.

The project tests the hypothesis that current informed consent procedures do not adequately address either the philosophical or practical difficulties of obtaining consent that can justify the collection, processing and disclosure of genetic data. The researcher working on the project is Dr Neil Manson. A monograph by Onora O'Neill and Neil Manson is soon to be published.

### Research based outside Cambridge

I am involved in the following collaborative projects:-

Legal Services Commission. FAINS action research. Professor Jan Walker, University of Newcastle and others.

Swedish Council for Social Research. Conflict, negotiation and decision making post divorce with Helena Willén, Nordic School of Public Health, Gothenberg.

Canadian Institute of Health Research. Ethics of Health Research and Policy. Ph.D. and Post Doc Training Programme. Centre for Applied Ethics, University of British Columbia and Dept of Philosophy, Dalhousie University.

Genome Canada and Genome British Columbia. Genomics, Ethics, Environment, Economic, Law and Society (GE3LS) Dr. M. Burgess and others, Centre for Applied Ethics, University of British Columbia.

Work continues on the book being written with Laura Riley which has the working title of 'Biotech Babies'. The book is concerned with what is popularly referred to as 'designer babies' and will trace developments from the human selective breeding experiments of the 19<sup>th</sup> century through eugenic policies and practices and current practices of prenatal and pre-implantation screening and diagnosis and of reproductive technology to possible futures. Papers have been published on the nineteenth century Oneida selective breeding experiment.

I am co-organiser of the Cambridge Socio-Legal Group Seminar on 'Kin & Care'. This was held in Cambridge in September 2005. Like other seminars in this series the seminar was based on discussion of pre-circulated papers. The book resulting from these is expected to be published in early summer, 2006. This will be edited by Bridget Lindley, Fatemeh Ebtehaj, Michael Lamb and Martin Richards

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I am a Director of the (Cambridge) Centre for Medical Genetics and Policy (until September 2005) and on the Advisory Board for the Cambridge Genetic Knowledge Park and for CESAGen.

I have been a member of The Wellcome Trust Biomedical Ethics Panel. My term ended in June 2005.

I continue to serve on the Human Genetics Commission and I co-chair a working party on Reproductive Decision Making and Genetics and am a member of the working group on genetic identity and relationship testing.

I am a member of the Human Fertilization and Embryology Authority's Ethics and Law Committee and the HGC observer on the Authority.

I am a member of the International Advisory Group for the MRC Data Sharing and Preservation of the Neonatal Blood Spot Screening Collections.

In March I gave the 2005 Enkin Lecture at McMaster University, Canada, 'Reproductive Choice and New Genetic and Reproductive Technologies'.

#### Recent Publications

Richards, M.P.M. (2004), "Perfecting people: selective breeding at the Oneida Community 1869-1879 and the eugenic movement", *New Genetics and Society*, 23, 49-71.

Richards, M.P.M.(2004), "DNA families", *Biological Sciences Review*, 16, 8-11.

Richards, M.P.M. (2004), "A 19<sup>th</sup> century experiment in human selective breeding", *Nature Reviews: Genetics*, 5, 475-479.

Halliday, J.L., Collins, V.R., Aitken, M.A., Richards, M.P.M. and Olsson, C.A. (2004), "Genetics in public health - evolution or revolution?" *J. Epidemiol. & Community Health*, 58, 894-899.

Clarke, A., Richards, M., Kerzin-Storrar, L., Halliday, J. et al, (2005), "Genetic professionals' reports of nondisclosure of genetic risk information within families", *European J. Human Genetics*, 13, 556-562.

**Ms Helen Statham**

***Senior Research Associate and Deputy Director***

Ongoing research

The Wellcome Trust funded research - *Psychosocial effects of molecular genetic diagnosis: the case of X-linked learning disability* – is a longitudinal study which follows families who have joined the Genetics of Learning Disability (GOLD) Study. The GOLD study aims to identify genes associated with learning disabilities in families currently without any specific diagnosis. The pattern of learning disability in the families suggests that it is likely that the condition is inherited in an X-linked way, i.e. the faulty gene is carried in females where it is not usually expressed, any son has a 50% chance of inheriting the faulty gene and in that situation, the boy will be affected. Although the psychosocial study is focussed on examining the beliefs, understandings, attitudes and behaviours of family members before and after genetic testing, we are also interested in other aspects of family life and the way in which these families are, or are not, supported by statutory services.

The study has been recruiting families to the study over the last year from all across the United Kingdom; we have interviewed members of 89 families, including mothers, fathers, sisters, brothers, grandparents and men who are themselves affected with a learning difficulty or disability. A few of the families are just starting to be given genetic information. The data collected in interviews relate to aspects of family life when one or more family members has a learning disability; perceptions and explanations of the disorder in the absence of a genetic diagnosis; family relationships and communication; and experiences and expectations of participation in the GOLD study.

A paper was given at the Seattle Club, a meeting for active researchers in learning disabilities held in December 2004 in Cambridge which talked about our data concerning why family members had agreed to take part in genetic research. This is now in draft stage prior to submission to publication, as is the submission we made to the Human Genetics Commission as a contribution to its public consultation on Genetics And Reproductive Decision Making. We contributed to a patient and public involvement project carried out by the Cambridge Genetics Knowledge Park which looked at the interface between learning disabilities and genetics and produced guidelines for the genetic investigation of children with undiagnosed developmental delay. Data was also contributed to the Eurogentest Network of Excellence (see below) The coming year will see an increase in the number of families told that a gene has been found and we will revisit those families to discuss with them the implications of the genetic diagnosis.

New research in the past year

I have become involved in two new research projects in the past year. The first is a small-scale collaboration with members of the Fetal Medicine Unit, Dr Andy Breeze and Mr Christoph Lees, at the Rosie Maternity Hospital (Addenbrookes) in Cambridge in which we are attempting to examine the sensitive issues around parental decision-making about post-mortem examination of a baby after either a termination for a prenatally diagnosed fetal abnormality or the in utero death of a baby. The challenges of the early phases of what is essentially a pilot study have been around negotiating ethical committee approval for working in this sensitive area but early responses are interesting and suggest that even newly bereaved parents welcome the opportunity to participate in research. The second new study is EDIG – Ethical Dilemmas in Genetic and Prenatal Diagnosis. This has been funded by the EU and is collaboration with partners in Germany, Italy, the Czech Republic, Sweden and Greece. The study promises to yield challenging and stimulating interchanges between ethicists,

philosophers, psychoanalysts and me as the empirical researcher! Funding was agreed at the end of this year and further details will be available in the next annual report by which time the project will be up and running.

#### Previous research and other activities

My two recent previous research studies still generate considerable active interest. One paper arising from the Nuffield Foundation funded study on decision-making around caesarean section (with Jane Weaver, now at Thames Valley University) has been published, another is submitted (see below) and there is considerable interest in the media from time to time when reports of our findings are 'discovered'. The findings of the studies funded by the NHS R&D and the Wellcome Trust, (carried out with Jo Green, University of York and Wendy Solomou, now at Dept of Land Economy, Cambridge) which investigated psychological, social and service implications of prenatal diagnosis and parental decision making continue to be of interest to a range of professional groups: a paper was given at the annual education meeting of SPROGs (Specialist Registrars in Obstetrics and Gynaecology) . and further publications are planned. I maintain my work with the voluntary sector group Antenatal Results and Choices to translate research findings into practice and this year has seen the publication of a handbook for professionals supporting parents in decision-making.

The ESRC-funded Innovative Health Technology Project: *Social implications of one-stop first trimester prenatal screening*, of which I have been a member of the Advisory Body has finished this year. The DIPex project on patients' experiences of ending a pregnancy is nearing completion. An additional European venture was a role as Expert Witness at a Consensus Workshop on Technology Assessment and Genetic Testing. The workshop was held in Seville as a contribution to the EUROAGENTEST Network of Excellence. Under the title 'Ethical, social and governance aspects of genetic testing services: what can we learn from the Technology Assessment approach and other recent studies in the field?' it sought to integrate views on and attitudes to genetic testing from Technology Assessments, empirical research and the patient perspective. It has been co-ordinated by two branches of The Joint Research Centre of the European Commission, viWTA (Flemish Institute for Science and Technology Assessment) and IPTS (Institute for Prospective Technological Studies in Seville).

#### Publications

Dimavicius, J., Gillott J. and Statham H. (2004), "Antenatal screening for chromosome, genetic and structural abnormalities", in E. Lee (ed), *Late Abortion: A Review of the Evidence*, Pro Choice Forum, London, 20–21.

Statham, H., Gillott J. and Dimavicius, J. (2004), "Termination of pregnancy after prenatal diagnosis", in E. Lee (ed), *Late Abortion: a Review of the Evidence*, Pro Choice Forum, London, 21-24

Weaver, J. J. and Statham, H. (2005), "Operative birth and psychological issues", *British Journal of Midwifery*, 13, 370 – 373.

Jones S, Statham H and Solomou W (2005), "When expectant mothers know their baby has a fetal abnormality: exploring a crisis of motherhood through qualitative data mining", *Journal of Social Work Research and Evaluation*, 6, 195 – 206.

**Ms Shirlene Badger*****Ph.D Student - funded by the Wellcome Trust Biomedical Ethics Programme***

***A genetic diagnosis for obesity: social and moral experiences of the body and responsibility in childhood. Funded by the Wellcome Trust Biomedical Ethics Programme (Supervised by Dr Oonagh Corrigan).***

The aim of my PhD research is to explore what happens when children who are severely obese and their families are recruited to a genetics of obesity study and the impact of receiving (or not receiving) a genetic diagnosis for obesity in their family.

Other activities:

During the last academic year I supervised an undergraduate dissertation student within the Faculty. I have continued my involvement in the organisation of the Cambridge Body Research Group which most significantly, involved a farewell mini – conference on 19 January 2005 ‘Body and Society: Contemporary Themes and Future Prospects’ as a celebration of Professor Bryan Turner’s contribution to the sociology of the body. I have also presented the following papers:

*Encountering the juncture between genetics and obesity in the body of a child*, 2nd International CESAGEN Conference, 12<sup>th</sup>-14<sup>th</sup> April 2005.

*The politics of obesity: encountering debates about culpability and geneticisation in the body of a child*, Centre for Family Research Genetics and Society Meeting, 9<sup>th</sup> May 2005.

*From mouse to child: constructing evidence in genetics of obesity research*. 9<sup>th</sup> Annual Postgraduate Forum on Genetics and Society Colloquium, 31<sup>st</sup> August - 2<sup>nd</sup> September 2005.

*A case of childhood obesity: Personal tragedy, familial trouble or public issue?* 37<sup>th</sup> Annual BSA Medical Sociology Conference, 15<sup>th</sup>-17<sup>th</sup> September 2005.

**Dr Elizabeth Chapman**Research Interests

Body image, Psychosocial aspects of pain, Cystic Fibrosis, Transplantation, HIV, Palliative care, Mechanical heart assist devices

Publications

Chapman, E., Bilton, D. et al (2005), “End of life care for adult cystic fibrosis patients: facilitating a good enough death”, *Journal of Cystic Fibrosis* (In press)

Chapman, E., Hughes, D., Landy, A., Whale, J., Saunders, M. (2005), “Challenging the representations of cancer pain: Experiences of a multidisciplinary pain management group in a palliative care unit”, *Palliative and Supportive Care*, Volume 3, 1-7.

Current research:

Psychological aspects of care for patients and supporters of patients with mechanical heart assist devices, Papworth Hospital NHS Foundation Trust.

Cystic Fibrosis – palliative care, transplantation, family interactions, treatment adherence, Papworth Hospital NHS Foundation Trust

Pain in cancer – Working with the multidisciplinary pain team, Arthur Rank Hospice

Psychological input to the musculo-skeletal pain service, Addenbrookes Hospital NHS Foundation Trust.

#### Conferences

Interactions between Psychological and Physical Aspects of CF: Follow up Annual Review Results. The 28<sup>th</sup> European Cystic Fibrosis Conference, June 2005, Crete.

I am Associate Editor: *Body Image: An International Journal of Research*, Elsevier Science.

#### **Dr Oonagh Corrigan**

*Centre for Family Research and Cambridge Genetics Knowledge Park*

*In August 2005 I moved to a Lectureship in Sociology at the University of Plymouth.*

#### Research interests

I am interested in the ways in which new biomedical technologies are shaped by social, political, economic and ethical forces, and the relationship these technologies have with various key players and stakeholders. My research interests lie primarily in the interface between the laboratory and the clinic. My areas of research include human genetics, clinical trials, informed consent, stem cell research, DNA and human tissues sample collections for genetic research, and scientific and lay understanding of risk.

#### Current research

During the past year I have carried out some preliminary work on the socio-ethical aspects of stem cell research. I have highlighted a number of issues in need of further study including the global aspects of human tissues trade and exchange. Also, together with Richard Tutton, a colleague at the University of Nottingham, we are carrying out an initial study into the conceptualisation of patient and healthy volunteers involved in biomedical research from that of 'subjects' to the current understanding of them as 'participants' in research.

#### Publications

Corrigan, O.P. (2005), "Pharmacogenetics, ethical issues: review of the Nuffield Council on Bioethics Report" commissioned review article, *Journal of Medical Ethics*. 31, 144-148

Corrigan, O. P. (2005), "Morality, risk and informed consent in clinical drug trials", in N. Redclift (ed), *Contesting Moralities: Science, Identity, Conflict*, London, UCL Press, 59-74

Corrigan, O.P, Liddell, K., McMillan, J., Stewart, A., and Wallace, S. (2005), "Ethical legal and social issues in stem cell research and therapy", briefing paper, Cambridge Genetics Knowledge Park

#### Presentations

'Towards a sociology of informed consent in the context of biomedical research' *Annual Meeting of the Eastern Sociological Society*, Washington DC, USA, March 19, 2005.

'Where does bioethics come from?' Centre for the Study of Invention and Social Process, Sociology Department, Goldsmiths College, University of London, 7<sup>th</sup> March 2005

'Origins and evolutions of bioethics', *Cambridge Bioethics Forum*, 23<sup>rd</sup> November 2004

'Evidence-based policy' *Social Science Workshop, Genetics Knowledge Parks Conference*, Weetwood Hall, Leeds, October 12, 2004



“They’re my genes” –the bioethics debate surrounding human genome research’, lecture for the BA Festival of Science, University of Exeter, Sept. 10 2004.

### **Dr Marc de Rosnay**

#### ***Centre for Family Research, Churchill College Junior Research Fellow***

My area of research concerns children’s emotional development, including their emotion understanding (i.e., the capacity to treat emotion as an object of knowledge) their emotional competence (i.e., the capacity to regulate and attenuate emotional experience), and the relationship between these factors. Following from my doctoral research, I am continuing to explore (i) children’s capacity to link their understanding of the nature of mind with emotion (e.g., How do children come to integrate their understanding of false belief with an emotional outcome?), and (ii) the link between maternal discourse, attachment and children’s emotion understanding.

This year, in conjunction with collaborators from the University of Durham (Dr E. Meins, Dr C Fernyhough, B. Arnott, & L Vittorini), we were awarded an ESRC grant (*Internal working models and young children’s social-emotional development*, No. 000231073, value: £ 316,000) to follow-up a large community sample of children in the North East of England. I am also collaborating with Profs. Cooper and Murray in Reading, where we are looking at infants’ sensitivity to maternal emotional responses in a social environment. This research is part of a large-scale longitudinal project on the intergenerational transmission of social anxiety.

Here in Cambridge, I have been actively involved in Co-Editing a Special Issue of the *British Journal of Developmental Psychology* that focuses on the importance of conversation for children’s developing social cognitive development. The Special Issue is due for publication early next year (2006). I am also currently preparing an additional grant application for submission to the ESRC.

#### Publications

de Rosnay, M., Cooper, P., Tsigaras, N. and Murray, L. (2005, in press), “Transmission of social anxiety from mother to infant: An experimental study using a social referencing paradigm”, *Behaviour Research & Therapy*.

Pons, F., Doudin, P.-A., Harris, P. and de Rosnay, M.(2005, in press), Emotion understanding: Development, individual differences, causes and interventions, in F. Pons, D. Hancock, L. Lafortune and P.-A. Doudin (eds.), *Emotions in Children and Pupils*, Aalborg, Aalborg University Press.

Harris, P. L., de Rosnay, M., and Pons, F. (2005), “Language and children’s understanding of mental states”, *Current Directions in Psychological Science*, 14(2), 69-73.

Pons, F., Harris, P. L., and de Rosnay, M. (2004), “Emotion comprehension between 3 and 11 years: Developmental periods and hierarchical organization”, *European Journal of Developmental Psychology*, 1(2), 127-152.

de Rosnay, M., Pons, F., Harris, P. L. and Morrell, J. M. B. (2004), “A lag between understanding false belief and emotion attribution in young children: Relationships with linguistic ability and mothers’ mental-state language”, *British Journal of Developmental Psychology*, 22(2), 197-218.

**Dr Claudia Downing*****Wellcome Trust Research Fellow in Biomedical Ethics (Jan 2002 – April 2006)***Research Interests

Studying everyday ethical issues that arise for members of families facing late onset hereditary risk late onset genetic disorders with a view to developing a framework in which to explore these concerns in relation to a range of genetic disorders and risks which share some of these characteristics but which are not necessarily genetic. Developing a process model of personal decision-making that acknowledges the family context and processes in which decision making occurs and how decision-making shapes identity. Qualitative methods including the use of computerized qualitative data analysis packages, and developing innovative ways of presenting qualitative data.

Current research

***Parenting in the space between health and illness: a comparative study of ethical dilemmas arising from the certain knowledge of a gene positive status for Huntington's disease and Myotonic Muscular Dystrophy.***

Aims of the study

- to explore and document the ways in which ethical issues around parenting shape decision-making about predictive testing for late-onset genetic disorders,

- to clarify and compare the ethical dilemmas that arise when mothering or fathering in the certain knowledge that one parent is at-risk for or will be affected by a late-onset dominant genetic disorder in the future,

- to compare experiences of two late-onset dominant disorders, Myotonic Muscular Dystrophy and Huntington's disease,

- to consider how factors such as gender, certainty/uncertainty of genetic risk status, age of dependent children and relationships impact on how parenting is experienced at this time,

- to identify the nature of concerns that genetic information raises for parents in their interactions with professionals

- to disseminate information about the findings about mothering and fathering to families and professionals identified as having an interest in this information.

Work is continuing on this study. The Wellcome Trust have very generously agreed to further extend my fellowship until the end of April 2006 to reflect the considerable period of time spent over the last two years on compassionate leave for family reasons. I am also completing more papers from my PhD work that will be submitted in the near future.

Publications

Downing, C. 2005 "Negotiating responsibility: case studies of reproductive decision-making and prenatal genetic testing in families facing Huntington disease", *Journal of Genetic Counseling*, 14, 3, 219-234.

Downing, C. 2005 "Negotiating appropriate housing: experiences of parents facing late-onset genetic disorders", *Disability, Pregnancy & Parenthood International*, 50, 12-13.

Conference and seminar presentations

*Parenting and late-onset genetic disorders: negotiating appropriate housing.* Paper presented at The Future of Disabled Parents' Research, 6<sup>th</sup> Seminar in the ESRC Funded Seminars on Disabled Parenting, University of Leicester, December 2004.

*Living with intellectual disability: parents' experiences in families facing two late onset genetic disorders, Huntington's disease and Myotonic Dystrophy.* Poster presented at: 4<sup>th</sup> Seattle Club Conference, University of Cambridge, December 2004.

*Pluralities of time: families facing late-onset genetic disorders in a molecular age* Paper presented at: British Sociological Association, Families Study Group, "Time, Space and Family Practices: A Dialogic Conference", Keele, Jan 2005,

*Conceptualizing responsibility.* Paper presented at: CFR-Cardiff University Update meeting, Gregynog, July 2005

#### Other activities

- Organized the CFR Seminar Program.
- Submitted a response to the Human Genetics Commission document, Choosing the Future.
- Joined the editorial board of the *Journal of Qualitative Studies on Health and Wellbeing*, to be published by Taylor & Francis, from March 1996.

### **Ms Rosie Ensor**

#### **Ph.D. student**

***Toddlers 'At-Risk' of Developing Behaviour Problems: The Role of Interactions with Caregivers. Funded by the PPP Foundation (supervised by Dr. Claire Hughes) Commenced September 2002 – September 2005***

I submitted my PhD thesis entitled 'Child and Family Influence on Early Prosocial Behaviour' on the 30<sup>th</sup> September, and am about to commence a one-year ESRC Postdoctoral Fellowship.

In addition, I attended the Society for Research in Child Development Biennial Meeting in Atlanta, and presented two papers. I also supervised the final year dissertation work of three undergraduate students, and for the second year undergraduate Experimental Psychology course.

#### Publications

Ensor, R. and Hughes, C., (in press), "More than talk: relations between emotion understanding and positive behaviour in toddlers", *British Journal of Developmental Psychology*.

Hughes, C. and Ensor, R., (in press), "Theory of mind and executive function in two-year-olds: a family affair?" *Journal of Developmental Neuropsychology*.

Hughes, C. and Ensor, R., (in press), "Behavioural problems in two-year-olds: links with individual differences in theory of mind, executive function and negative parenting?" *Journal of Child Psychiatry and Psychology*.

Hughes, C, Fujiswara, K., Ensor, R., Lecce, S. and Marfleet, R., (in press), "Cooperation and conversations about the mind: a study of individual differences in 2-year-olds and their sibling", *British Journal of Developmental Psychology*.

#### Presentations

Ensor, R. (April, 2005). Mother-Child Talk and Early Problem Behaviours: Exploring the Links. Paper presented to Society for Research in Child Development Biennial Meeting, Atlanta.

Ensor, R., & Hughes, C. (April, 2005). Early social understanding and prosocial behaviour:

The contextual importance of mother-child mutuality. Paper and poster presented to Society for Research in Child Development Biennial Meeting, Atlanta.

Hughes, C., Ensor, R., Fujiswara, K., & Lecce, S. (April, 2005). Links between early inner state awareness and quantity, quality, and connectedness of maternal talk. Paper presented to Society for Research in Child Development Biennial Meeting, Atlanta.

Ensor, R. & Hughes, C., (Dec 2004), On the importance of being consistent: Maternal predictors of verbal ability gains from 2- to 3-years in an at-risk sample. Paper presented to Seattle Club, Cambridge.

Ensor, R. A. & Hughes, C., (Oct 2004), More than Talk? Comparing Social Understanding and Verbal Ability as Predictors of Prosocial Behaviours of Toddlers with Young and Not Young Mothers. Poster presented to Centre for Research in the Arts, Social Sciences, and Humanities, Cambridge.

### **Dr Gail Ewing**

#### ***Research Associate (part time)***

#### Research studies

##### End of Life Care and its Importance to Family and Friends:

With Dr Gunn Grande, School of Nursing, Midwifery and Social Work, University of Manchester and the National Forum for Hospice at Home.

This is a pilot project funded for one year from January 2005. The purpose is to investigate circumstances surrounding death at home and the effects on family caregivers in bereavement. The project will examine how people's preference for a place of death, having that preference fulfilled and actual place of death influence caregiver bereavement.

##### District nurses' 'early support visits': How district nurses, cancer patients and their carers construct and conduct pre-terminal visits:

With Dr Margaret Rogers and Dr Jane Griffiths, School of Nursing, Midwifery and Social Work, University of Manchester.

This project is scheduled to start in October 2005. We know that district nurses prefer to provide support visits to patients as early as possible to get to know them before complex physical care is needed during the terminal phase. What is unclear is whether this is happening, and if so, how effective it is. This is a small scale project to investigate 'early support visits' in order to understand their nature and their benefit to palliative care patients and their informal carers.

##### Symptoms and Needs Assessment in the Provision of Palliative Care in the Community.

With Professor Chris Todd, Dr Margaret Rogers and Dr Jane Griffiths, School of Nursing, Midwifery and Social Work, University of Manchester and Dr Stephen Barclay, Institute of Public Health, University of Cambridge.

Further analysis of data on community based palliative care provided to patients and their lay carers by district nurses and general practitioners.

#### Publications:

Ewing G, Rogers M, Barclay S, McCabe J, Martin A, Campbell M, Todd C, "Palliative care in primary care: do patients and professionals agree on symptoms", *Br J Gen Pract* (in press).

Griffiths J., Ewing G, Rogers M, Barclay S, McCabe J, Martin A, Todd C. "Supporting cancer patients with palliative care needs: district nurses' role perceptions", *J Adv Nurs* (in review).

Barclay S, McCabe J, Ewing G, Martin A, Rogers M, Addington-Hall J, Todd C. (2005), "How accurate are GPs' prognostic estimates?" *Fam Pract* 22, Suppl 1 (Abstract).

Ewing G, Rogers M, Barclay S, McCabe J, Martin A, Todd C (2004), "Recruiting patients into a primary care based study of palliative care: why is it so difficult?" *Palliat Med*, 18, 452-9.

Ewing G, Todd C, Rogers M, Barclay S, McCabe J, Martin A. (2004), "Validation of a symptom measure suitable for use among palliative care patients in the community: CAMPAS-R", *J Pain Symptom Manage*, 27, 287-99.

Todd C, Ewing G, Barclay S, Rogers M, Martin A, McCabe J *et al.* (2004), *Palliative Care in Primary Care: Report to the Department of Health.*

### **Dr Tabitha Freeman**

#### ***Junior Research Fellow, St. Edmund's College***

My main field of research is gender, reproduction and the family, with a particular focus on masculinities and fatherhood; feminist and psychoanalytic theory; and new genetic and reproductive technologies. This year, I have developed my interest in DNA paternity testing by examining the cultural and theoretical implications of this technology for concepts of parentage and kinship, enabling me to build upon my PhD research on fatherhood. I have also prepared several journal articles and a book proposal based on my PhD thesis, to be submitted in the forthcoming academic year. I am continuing to seek project funding for research on the psychosocial and ethical implications of paternity testing in collaboration with Prof. Martin Richards.

In addition, I have applied my background in gender studies to research on women's employment experiences in academic/research institutions. I am currently involved in various projects looking at equality, diversity and work-life balance issues in science, engineering and technology in both academia and industry. This includes a European survey addressing gender and career development in nanotechnology (based at the Nanoscience Centre with Dr Steffi Friedrichs), and current proposals to develop similar research projects in the sphere of computer science (with Intellect) and atmospheric science (with Dr Neil Harris).

#### Conference and seminar presentations

Freeman, T. & Richards, M. 'DNA testing and kinship', Cambridge Socio-Legal Group, University of Cambridge, September 2005.

Freeman, T. 'Paternity and kinship: social aspects of DNA testing', Cardiff-Cambridge Joint Social Science & Genetics meeting, University of Cardiff, July 2005.

Freeman, T. 'Fatherhood and paternal uncertainty: the cultural and theoretical significance of DNA testing', Centre for Gender Studies seminar, University of Cambridge, June 2005.

Freeman, T. 'Fatherhood: current research and policy', invited speaker at *Behavioural Studies Conference: Applications and Future Directions*, West Suffolk College, May 2005.

Freeman, T. 'Changing fathers, changing history: an evaluation of historical narratives of fatherhood', Centre for Family Research seminar, University of Cambridge, October 2004.

### Publications

Freeman, T. and Richards, M. "DNA testing and kinship: paternity, genealogy and the search for the 'truth' of genetic origins", in B. Lindley, F. Ebtehaj, M. Lamb and M. Richards (eds), *Kinship: Relationships and Law in a Changing Society*. Oxford: Hart. Forthcoming 2006.

Freeman, T. "Psychoanalytic perspectives on fatherhood: patriarchal paradoxes and the presence of an absent authority". Short-listed for *Psychology of Women Section Review* (British Psychological Society) essay prize. To be submitted to *Psychoanalysis, Society and Culture*.

### Teaching

#### *At Cambridge:*

- Supervisor and examiner for 'Modern Societies' (Part 1, Paper 2);
- Supervisor and seminar presentation for 'Biotechnologies and Society' (Part IIb, Int 4);
- Studies skills supervisor.

#### *Other:*

- Lecturer for 'Gender Divisions in Contemporary Society' (SC902), MA in Gender Studies, University of Essex;
- Examiner for 'Cultural Change in Contemporary Society' (SC224), 2<sup>nd</sup>/3<sup>rd</sup> year undergraduate course, University of Essex.

### Other research activities

- Qualitative data analyst for the Staff Satisfaction Survey and Women's Forum, Equality and Diversity Office, University of Cambridge;
- Principal researcher on European survey of gender and work-life balance issues in nanotechnology for the Frontiers Network of Excellence research programme (funded by the European Commission, March - October 2005), Nanoscience Centre, University of Cambridge.

### **Ms Zeynep Gürtin-Broadbent**

#### *PhD Student – funded by the ESRC*

#### *Patients' experiences and constructions of Fertility Treatments, with a particular interest on cultural variations*

I joined the Centre in October 2004 as a PhD student. My research looks at the ways patients construct, experience and make sense of the fertility treatments they are undergoing. I am particularly interested in cultural variations in patients' responses and approaches to treatment. I work qualitatively, employing a mixture of ethnography and interviewing techniques, to enable the patients' perspectives to come across as richly as possible. I have spent a large part of this year in clinics across the UK, observing clinical procedures and staff-patient interactions.

### Supervising

This academic year, I have supervised for the Social Theory, Interdisciplinary Methods, Philosophy of Social Science and Modern Societies papers in the SPS Tripos.

### Presentations

'Multi-Cultural Patient Experiences and Constructions of Fertility Treatment', *Cardiff – Cambridge Joint Social Science and Genetics Meeting*, Gregynog 12<sup>th</sup> – 13<sup>th</sup> July 2005.

'Beyond the Wall: Public Discourses of Ignorance and Indifference in the Embryo Research Debate', *6<sup>th</sup> Inter-University Graduate Conference: Challenging the Boundaries in the Social Sciences*, Cambridge 21<sup>st</sup> May 2005.

'Conceiving the Embryo: Public Perceptions of Embryos and Attitudes to Embryo Research', *CESAGen 2<sup>nd</sup> International Conference: Genomics and Society*, London 12<sup>th</sup> – 14<sup>th</sup> April 2005.

'Ethnography of a Fertility Clinic: Clinical Constructions and Patient Experiences of Fertility Treatment', *King's College Lunchtime Seminar*, Cambridge 25<sup>th</sup> February 2005.

### Conferences

Eric Jensen and I are currently organising the 'Talking Embryos' Conference, funded by the Centre for Research in Social Science, Arts and Humanities, to take place in May next year.

I am also involved in organising the first 'Free School Lane Reproduction Conference', which will take place in October 2005. This conference aims to build collaborative relationships between individuals working on aspects of reproduction across the neighbouring SPS, HPS and Social Anthropology departments in Free School Lane.

In February this year, along with two other students, I was chosen to write the conference report following the 'Medicine, Gender and Sexuality' workshop held at Cambridge University's Centre for Research in the Arts, Social Sciences and Humanities as part of the AHRC's Arts, Humanities and Medicine Workshop Series in association with the Nuffield Trust.

### Other Activities

Research Assistant - For the past two summers, I have been volunteering as a research assistant for the Toddlers Up study, ran by Claire Hughes.

SPS Graduate Faculty Representative.

## **Dr Joanna Hawthorne**

### ***Senior Research Associate***

***Research concerns parent-child relationship and infant development especially in neonatal units.***

### Publications

Alderson, P., Hawthorne, J., Killen (2005), "The participation rights of premature babies", *The International Journal of Children's Rights*, 13, 31-50.

Hawthorne, J. (2005), "Understanding the neonatal Behavioural Assessment Scale. Four articles for Polish Nursing journal:

Hawthorne, J.T. (2004), "Psychological aspects of neonatal care", Chapter in Robertson's *Textbook of Neonatology, Fourth Edition*. Edited by Janet M. Rennie, Churchill Livingstone, London.

Hawthorne, J. (2004), "The Brazelton Centre in Great Britain: Training health professionals in the Neonatal Behavioural Assessment Scale." Article for The Signal, Newsletter of the World Association for Infant Mental Health.

Hawthorne, J. (2004), "Understanding the psychological aspects of parenting and understanding baby behaviour", in "Working with Young Parents", Young parents and MIDIRS collaborative project.

Hawthorne, J., Hutchon, B. (2004), "The NBAS in community health settings: the UK, in T.B. Brazelton, B. Petrauskas and J.K. Nugent (eds), *Looking Back, Looking Forward: What We Now Know About Newborn Infants and Their Families and What we Need to Do Next*, Johnson and Johnson Pediatric Institute, LLC. (in press).

Hawthorne, J, Alderson P, Killen M. (2005), "Belonging: parent-infant relationships around transfer and discharge from neonatal units". *Infant*. (in press).

Hawthorne, J (2005), "Support for parents in a Neonatal Unit using the Neonatal Behavioural Assessment Scale". *Infant*. (in press).

#### Leaflet

Hawthorne, J. (2005), Getting to Know your Baby: Using the Brazelton Neonatal Behavioural Assessment Scale (NBAS). Leaflet for the NICU, Addenbrookes NHS Trust, Cambridge

#### Other activities

Coordinator of the Brazelton Centre in Great Britain which aims to promote an understanding of infant behaviour, and foster strong parent-infant relationships through research, and training for health professionals in the NBAS: I administrate, teach, train and organise study days and workshops. Training multi-disciplinary groups in Sure Start areas. Invited workshops.

Founder and organiser of the Infant Relationships Study Group – termly meetings on clinical and research topics concerning early relationships.

Enriching early relationships, international conference, March 4,5, 2004 London. Organised for the Brazelton Centre in Great Britain, sponsored by the Johnson & Johnson Pediatric Institute.

Committee Member of CAMPIP - Cambridge Parent-Infant Project (infant mental health group), Parents First! and Developmental Care Group, NICU, Rosie Hospital

Honorary contract at the Rosie Hospital, Addenbrookes NHS Trust, Cambridge: Providing intervention for parents of babies in the NICU using the NBAS; teaching staff.

Sustaining member of the Board of Directors, Chicago Lying-In Hospital, Chicago.

Planning conference, Understanding Newborn Behaviour, March 2006, Cambridge

Scientific consultant for BigWave TV on DVD: Baby Thoughts



**Dr Claire Hughes*****Predicting antisocial behaviour and peer problems.******Funding: The Health Foundation (formerly known as the PPP Foundation)******Funding period: October 2002-2005 £215K******Co-applicant Professor Judy Dunn, Institute of Psychiatry, London.***

Claire Hughes is a Fellow of Newnham College, Cambridge, and a Senior Lecturer in Developmental Psychology at the Faculty of Social & Political Sciences (with a promotion to Reader from October 2005). She is an editor for the journal *Infant and Child Development* and *British Journal of Developmental Psychology* and her research interests include developmental psychopathology (including disruptive behaviour and autism) and individual differences in early social and cognitive development. Her current research includes a longitudinal study of social and cognitive development in an at-risk sample of young children (funded by the Health Foundation, and in collaboration with Professor Judy Dunn).

Research interests:

My current research focuses on the early origins of antisocial behaviour and peer problems. My research team are currently concluding the final phase of this study, which involves filming 240 children in 70+ schools and nurseries. Our goal is to examine both the real-life implications of individual differences in social understanding and self-control for young children's close relationships with family and friends, and the contribution of children's social relationships to their cognitive development.

The 'Toddlers Up' research team saw a few changes over the year –Laila Friese left the Centre for Family Research to spend more time with her own family and has been replaced by Dr Anji Wilson, who has done a sterling job co-ordinating all the student helpers involved in school visits. During the year we have had a number of research visitors, including Dr Isobel Roskam (from Belgium), Dr Serena Lecce (from Italy), Ms Keiko Fujisawa (from Japan) and Ms Jesse Leins (from the USA). Rosie Ensor has now completed her PhD thesis based on the first year of her data-collection for the project and will shortly be starting an ESRC-funded post-doctoral fellowship that will enable her to conduct longitudinal analyses, using transcripts and videos from home and lab-visits carried out across the first two years of the study. Recently, the study itself also received funding from the ESRC, for a two-year follow-up in which all the children (and their friends) will be seen in Year 1 of school. We hope that this will lead to some very interesting findings on children's developmental trajectories from toddler-hood to school-age!

In Michaelmas Term, along with Dr Marc de Rosnay I organised a one-day conference (co-funded by the Department of Social and Developmental Psychology and the Centre for Research in the Arts, Social Sciences and Humanities) on the theme of 'Conversations and Childhood'. This meeting was a great success, and has led to our co-editing a special issue of *British Journal of Developmental Psychology*, to appear in the spring of 2006.

Publications

Hughes, C., Graham, A. & Grayson, A. (2004), Executive function in childhood: development and disorder, in J. Oates (ed), *Cognitive Development*, Open University Press, 205-230.

Hughes, C., & Leekam, S. (2004). "What are the links between theory of mind and social relations? Review, reflections and new directions for studies of typical and atypical development", *Social Development*, 13, 590-619.

Kuntsi, J., Eley, T. C., Taylor, A., Hughes, C., Asherson, P., Caspi, A., & Moffitt, T. E. (2004), "The co-occurrence of ADHD and low IQ has genetic origins", *Neuropsychiatric Genetics, a section of the American Journal of Medical Genetics*, 124B, 41-47.

Ensor, R., & Hughes, C. (2005), "More than talk: relations between theory of mind, emotion understanding and positive social behaviour in toddlers. To appear in the November issue of *British Journal of Developmental Psychology*.

Hughes, C. (2005), "Origins of individual differences in theory of mind and language: Twin study findings", in J.W. Astington, J. Baird, P. Zelazo & D. Olson (eds), *Why Language Matters for Theory of Mind*, Oxford University Press, New York, 319-340.

Hughes, C. (2005), "Executive function and development, in B. Hopkins (ed), *Cambridge Encyclopedia of Child Development*, Cambridge University Press, 313-316.

Hughes, C. & Ensor, R., (2005), "Theory of mind and executive functions in two-year-olds: a family affair?" To appear in a special issue of *Developmental Neuropsychology*

Hughes, C. & Ensor, R. (2005), "Behavioural problems in two-year-olds: links with individual differences in theory of mind, executive function and negative parenting. To appear in *Journal of Child Psychology & Psychiatry*.

Hughes, C., Jaffee, S., Happé, F., Taylor, A., Caspi, A., Moffitt, T. (2005), "Origins of individual differences in theory of mind: From nature to nurture? *Child Development*, 76, 356-370.

#### In Press

Hughes, C., Lecce, S. & Wilson, C. (2005), "Do you know what I want? Preschoolers' talk about desires, thoughts and feelings in their conversations with sibs and friends". To appear in *Cognition and Emotion*.

Ronald, A., Happé, F., Hughes, C., Plomin, R. (2005), "the nature and nurture of nice and nasty theory of mind", to appear in *Social Development*.

Hughes, C., Fujisawa, K., Ensor, R., Lecce, S. & Marfleet, R. (2006), "Cooperation and conversations about the mind: a study of individual differences in 2-year-olds and their siblings", To appear in the *British Journal of Developmental Psychology*.

Happé, F.G.E., Hughes, C., Booth, R., Charlton, R. (2006), "Executive dysfunction in autism spectrum disorders and attention deficit/hyperactivity disorder: Developmental profiles", To appear in *Brain and Cognition* (special issue on Asperger's syndrome).

Hughes, C. & Dunn, J (2006). "Children's early relationships with other children" to appear in C.A. Brownell & C.B. Kopp (eds), *Transitions in Early Socioemotional Development: The Toddler Years*, Guilford Press.

#### Grant applications submitted in 04-05

Social and cognitive predictors of success in the transition to school – ESRC – funded.

Peer interactions in childhood – MRC – decision date: March 2006.

## Eric Jensen

*Ph.D student - funded by a Gates-Cambridge Scholarship*

*'Anglo-American Press Coverage of Therapeutic Cloning: A Grounded Discourse Analysis of News Production and Content'*

This is my third year at Cambridge. My PhD research addresses an important set of sociological issues raised by biomedical research on human cloning and embryonic stem cells, including concerns such as nationalism, hype, thin public debates, and technocracy. My research focuses on the framing and social construction of therapeutic cloning within the mediated public sphere. My PhD dissertation centres on the case of Anglo-American press coverage, combining data from in-depth interviews with science journalists at elite US and British news publications with sociological analysis of the actual content of their coverage.

### Publications

Weasel, Lisa H. and Jensen, E. (2005). "Language and values in the human cloning debate: A web-based survey of scientists and Christian fundamentalist pastors." *New Genetics and Society*, 24 (1), 1-14.

Jensen, E. and Weasel, Lisa H. (*In press*), "Abortion rhetoric in American news coverage of human cloning", *New Genetics and Society*.

Jensen, E. (*In press*), "The Dao of human cloning: Hope, fear and hype in the UK press and popular films", *Public Understanding of Science*.

### Presentations

Jensen, E. (2005), Therapeutic Cloning in the US and Britain: A Study In Progress. Presented at 2<sup>nd</sup> annual *Centres for the Ethical and Social Aspect of Genetics (CESAGen)* convention held at the Royal Society in London.

Science in the media. Lecture for *INT 4: Genetics and Society* (2004-2005) SPS Tripos.

Therapeutic Cloning in the US and Britain (2005), presented at *Faculty PhD Research Workshop* in Faculty of Social and Political Sciences, University of Cambridge.

### Other Academic Activities

- Together with Zeynep Gürtin-Broadbent, I am co-organising an academic conference, "Talking Embryos", bringing in speakers from across the arts and social sciences to speak on the social role of the embryo. The conference is funded by the Centre for Research in the Arts, Social Sciences, and Humanities (CRASSH) and will take place in May 2006 in Cambridge.

- I have begun reviewing manuscript submissions to the academic journal *Public Understanding of Science* as an anonymous expert peer reviewer.

- I have served as a reviewer for the Research Grants Board of the *Economic & Social Research Council*.

-I will be conducting one-day workshops on Computer-aided Qualitative Data Analysis as an Instructor for the Methodology Institute of the London School of Economics.

**Dr Lynne Jones*****Senior Research Associate***

My book on children's understanding of war in Bosnia, *Then They Started Shooting. Growing Up in Wartime Bosnia*, was published by Harvard University Press in 2004.

Currently working in the regions affected by the Indian Ocean Tsunami.

Jones, L., Rrustemi, A., Shahini, M. and Uka, A. (2003), "Mental health services for war affected children: report of a survey in Kosovo", *British Journal of Psychiatry*.

**Dr Shobita Parthasarathy**

***Research Fellowship, "Global Technologies for the Global Consumer: An Exploration of the Transnational Politics of the Genomic Age", Biomedical Ethics Programme, The Wellcome Trust, UK.***

***From September 2005 I have taken up an offer of an Assistant Professorship at the Ford School of Public Policy at the University of Michigan.***

Research interests/activities

I am interested in the comparative and international politics of genetics and biotechnology, particularly medical biotechnology. Specific topics of interest include: globalization and biotechnology; how national context influences the development of biomedicine; the role of patient advocacy groups in the conduct of biomedicine; the assignment and use of intellectual property in the area of biotechnology; the role and influence of the biotechnology industry; the influence of patient advocacy groups on scientific and medical practice; and science and democracy. More broadly, I do work in the fields of science & technology studies, medical sociology, political sociology, and bioethics.

Short description of project

I am currently completing my book, which is entitled, *Building Genetic Medicine: Disease, Technology, and the National Politics of Health Care*, which will be published by MIT Press. The book compares the development of genetic testing for breast cancer in the US and Britain. It argues that national context influences scientific practice and technological development, which has important consequences for citizens and the way we define good health care. Finally, it argues that such ties to national context make it particularly difficult to transfer a new technology to another country, even in this era of globalization.

My current research investigates the European politics over patenting biotechnology to explore how globalization figures in medicine and health care. Many scholars and popular writers argue that the world is becoming increasingly interdependent, with science and technology building bridges across national boundaries that are cemented by multinational corporations, transnational advocacy groups, and international laws. Attempts to globalize the biotechnology industry, however, have not been simple or straightforward. Both companies and industry lobby organizations suggest that in order to build a strong biotechnology industry in Europe, the European Union must create a robust intellectual property regime that resembles its American counterpart. They argue that patenting should be seen as it is in the US, a primarily technical process that requires input from skilled scientists, engineers, and lawyers. Many European governments and advocacy groups dispute this characterization, suggesting that decisions about, for example, the patentability of genes and stem cells, are not simply technical, but are simultaneously political, social,

economic, and moral. Development of a European biotechnology industry, they warn, must play explicit attention to each of these dimensions, in order to establish its legitimacy among the public. How does Europe negotiate between its efforts to innovate and its democratic and public health ideals in the development of a biotechnology industry? What are the implications for the conduct of genetics and biotechnology research and the provision of health care in Europe? What can these politics tell us about the processes of globalization? By investigating how debates about these issues unfold and are resolved, this systematic and in-depth empirical analysis will explore the challenges of globalization, its influence on the development of contemporary biotechnology and health care, and its consequences for the global citizen.

Other activities, lectures or presentations given

- 2005 Center for the Analysis of Risk and Regulation, London School of Economics, England.
- 2005 Seminar on Science and the Law, University of California—Irvine.
- 2005 Science Studies Reading Group, Cornell University, Ithaca, NY.
- 2005 Cambridge Genetics Knowledge Park and Centre for Family Research, University of Cambridge, England.
- 2005 Life Sciences & Society Symposium: The Social & Cultural Implications of New Biomedical Technologies, University of Missouri—Columbia.
- 2005 History of Science Colloquium, University of California—Los Angeles.
- 2004 Center for Society & Genetics Colloquium, University of California—Los Angeles.
- 2004 Kellogg School of Management, Northwestern University, Illinois.
- 2004 MacLean Center for Clinical Medical Ethics Seminar Series, University of Chicago.
- 2004 *Society for the Social Studies of Science/EASST* conference, Paris, France (paper presenter)
- 2004 *American Sociological Association* conference, San Francisco, CA (paper presenter).
- 2004 *Society for the Study of Symbolic Interaction* conference, San Francisco, CA.

Publications

Parthasarathy, S. “Building Genetic Medicine: Breast Cancer, Technology, and the National Politics of Health Care”, (Inside Technology Series), Cambridge, MA, MIT Press (forthcoming).

Parthasarathy, S., “Reconceptualizing technology transfer: the challenge of building an international system of genetic testing for breast cancer” in D.H. Guston and D. Sarewitz (eds), *Shaping Science and Technology Policy: The Next Generation of Research*, University of Wisconsin Press (in press).

Parthasarathy, S., “The patent is political: the consequences of patenting the BRCA genes in Britain”, *Community Genetics Supplement*. (in press).

Parthasarathy, S. (2005), “Architectures of genetic medicine: comparing genetic testing for breast cancer in the USA and UK”, *Social Studies of Science*, Vol. 35, No. 1.

Diermeier, D. and Parthasarathy, S. (2005), *Myriad (A): Breast Cancer Testing in the United States Case 5-304-503(A)* (Evanston, IL: Kellogg School of Management, Northwestern University).

Diermeier, D. and Parthasarathy, S. (2005), *Myriad (B): Breast Cancer Testing in the United States* Case 5-304-503(B) (Evanston, IL: Kellogg School of Management, Northwestern University).

Diermeier, D. and Parthasarathy, S. (2005), *Myriad (A): Breast Cancer Testing in Britain* Case 5-304-503(A) (Evanston, IL: Kellogg School of Management, Northwestern University).

Diermeier, D. and Parthasarathy, S. (2005), *Myriad (B): Breast Cancer Testing in Britain* Case 5-304-503(B) (Evanston, IL: Kellogg School of Management, Northwestern University).

Parthasarathy, S., (2004), Book Review: "The Breast Cancer Wars," and "A Darker Ribbon," *Isis*, 95, 728.

Parthasarathy, S., (2004), "Regulating Risk: Defining Genetic Privacy in the US and Britain." *Science, Technology, and Human Values*, Vol. 9, No. 3.

## **Mrs Maggie Ponder**

### ***Research Associate - part time***

#### Research activity

Co-worker with Helen Statham on the study - *Psychosocial effects of molecular genetic diagnosis: the case of X-linked learning disability*. We aim to follow families who have been recruited to the Genetics of Learning Disability (GOLD) Study. The GOLD study aims to identify genes associated with learning disabilities in families currently without any specific diagnosis but where the pattern of inheritance suggests X-linked inheritance. The psychosocial study will examine the beliefs, understandings, attitudes and behaviours of family members before and after genetic testing.

#### Other activities

- Trustee of the Neurofibromatosis Association.
- Chairman of the Genetic Interest Group.
- Member of the executive board of the Cambridge Genetic Knowledge Park.
- Consumer representative on the Genetic Commissioning Advisory Group (GenCAG).
- Member of the Cambridge Local Research Ethics Committee.

The Neurofibromatosis Association is a national charity set up to provide help and support to families affected by neurofibromatosis and raise money to support research.

The Genetic Interest Group is a national alliance of charities and groups representing people affected by all types of genetic disorders. The main purposes are to provide information for families and others, educate the medical professions about genetic disorders and influence policy for the benefit of people living with genetic disorders. The trustees have responsibility for overseeing the work and of strategic planning. I represent GIG at official meetings both in the UK and Europe.

**Dr Christine Rogers*****Post-Doctoral Research Fellow (ESRC)***

I came to the Centre as a postdoctoral research fellow having completed my PhD at the University of Essex. This one-year fellowship has been to disseminate her PhD research findings: *A sociology of parenting children identified with special educational needs: The private and public spaces parents inhabit*. From a sociological perspective the findings have emerged from qualitative research with parents who have children with learning impairments. The study mapped the parental negotiation of the education process: the provision of the child's education, the assessment and surveying of their 'special' educational needs (SEN), the struggles incurred, how this process effects the whole family and what the impacts of living with this process meant for the main carer in relation to their emotional and practical life.

In September 2005 I took up a Lectureship in Education at the University of Keele, School of Criminology, Sociology & Social Work.

Teaching activities

I have lectured on qualitative research methods to MRes and PhD Psychology students, and led seminars on Criminology to Sociology Undergraduates at the University of Essex.

Publications

Rogers, C. A. (2003), "The mother/researcher in blurred boundaries of a reflexive research process", *Auto/Biography* XI (1&2), 47-54.

Book reviews

Rogers, C. A. (2003), review of *Having Faith: An Ecologist's Journey to Motherhood*. The Perseus Press (2001) in *Sociology of Health and Illness* 25 (7) pp. 894-895.

Rogers, C. A. (2003), review of *Disability, Family and Society: Listening to mothers*. OUP (2000) in *British Journal for Learning Support* 18(1): pp 48.

Publications (forthcoming)

Lucey, H. and C. Rogers, "Power relationships between research students and their supervisors", in V. Gillies and H. Lucey (eds), *Power, Knowledge and the Academy: Exploring the Institutional and Personal Dynamics of Feminist Research*, Palgrave

Rogers, C. 'Experiencing an 'inclusive' education: Parents and their children with special educational needs (SEN)' *British Journal of Sociology of Education*

Book review

Rogers, C. (2005) review of *Social Research Methods* (second edition). OUP (2004) in *International Journal of Social Research Methodology: Theory and Practice* (in press).

Research dissemination

Rogers, C. 'Sexual identity and young adults with learning impairments: an engagement with autoethnography?' at *(Re)creating Methodologies, Practices and Concepts Symposium* (ESRC) Goldsmiths College, University of London 1-3 September 2005

Rogers, C. 'Parental experiences of 'special' education: inclusion or exclusion?' at *ISEC 2005: Inclusive and Supportive Education Congress*, University of Strathclyde, 1 – 4 August 2005.

Rogers, C. 'Parenting a child with impairments: identification, diagnosis and living with difficulty' at the *Colchester PCT Learning Disabilities Services Research Conference, in Collaboration with the APU*, APU, Chelmsford, 31 March 2005.

Rogers, C. 'The ambiguous space inhabited by parents with a 'disabled' child' presented at the *BSA Family Studies Group Conference 2005: Time, Space and Family Practices: a dialogic conference*, University of Keele, 14 – 15 January 2005.

Rogers, C. 'An overview of qualitative research on parenting children with impairments' *Seminar series paper* Centre for Family Research, Faculty of Social and Political Sciences, University of Cambridge, 23 November 2004

Rogers, C. 'Experiencing 'special' education: Parenting children with learning difficulties' presented at the *International Learning Conference 2004* Central Institute for Pedagogical Sciences, Cojímar, Havana City, Cuba 27-30 June.

Rogers, C. 'Mad and deranged? No just carrying out qualitative research: The parent/researcher in blurred boundaries of the research process and reflexive sociology' presented at the *British Sociological Association conference* University of York 11 - 13 April 2003.

Rogers, C. 'Whose problem are 'they' anyway? Parenting children with special educational needs: the web of contradictions in current legislation and directives' presented to *British Sociological Association conference* Leicester University, 27 March 2002.

Rogers, C. A. 'Negotiating emotions: parenting children with special educational needs' presented to *Centre for Educational Development, Appraisal and Research, (CEDER)* Warwick University, 18-19 March 2002.

## **Dr Ilina Singh**

### Research activities

2004 EU 6th Framework Programme: Genome-Based Drugs for Depression  
2007 ( McGuffin (PI), Rose (PI), Aitcheson, Singh) ELSI portion: 500,000 Euros  
Senior Researcher: 12 sites in Europe and the UK

I oversee and manage ELSI workpackage on patient attitudes and stigma; help develop research instruments; participate in data analysis and write up; supervise postdoctoral researchers.

1/2/2005 Department of Health: Mental Capacity and Emergency ECT  
31/10/05 (Hotopf (PI), David, Szmukler, McLoughlin, Richardson, Churchill, Singh)  
£59,778

Qualitative Methods Consultant

2003-present: Managing Editor, *BioSocieties: An international journal for social studies of life sciences*

Responsible for creation, design and editorial aspects of this new journal, with Professor Nikolas Rose (LSE) and Professor Anne Harrington (Harvard University). Forthcoming by Cambridge University Press in 2006.

### Talks

June, 2005: "Inside I may be evil": Children's experiences with ADHD diagnosis and medication. Oslo, Norway Childhoods 2005 Conference, University of Oslo

June, 2005: Risk Discourse in Developmental Psychiatry: Implications for Children and the Family London, UK, Risk Management and Mental Health Conference, City University



February, 2005: Interviews with ADHD Children: Methodological Challenges. Dublin, Ireland. Centre for Children's Research, Trinity College, Dublin  
 April, 2005: Not Just Naughty: 50 Years of Stimulant Drug Advertising, Manchester, UK, Centre for the History of Science, Technology and Medicine, Manchester University  
 January, 2005: Dosing Dilemmas for Parents of Boys Taking Ritalin for ADHD, Cambridge, UK. Gender Studies Seminar, Social & Political Sciences, University of Cambridge  
 December, 2004: Not Just Naughty: 50 Years of Stimulant Drug Advertising, London, UK, BPS History of Psychology Group, Imperial College  
 September, 2004: Moral Dilemmas and Ritalin Riddles, York, UK. BSA Medical Sociology Group Annual Conference  
 May, 2004 Moral Dilemmas and Ritalin Riddles

#### Invited workshops

June 2004 Participant: Ethics and Mental Health Workshop, Wellcome Trust, London  
 January 2005 Participant: MRC Neuroethics Workshop, MRC, London  
 March 2005 Expert discussant: Pharmacogenomics Focus Groups, Royal Society, London  
 Sept. 2005 Invited Speaker: Wellcome Trust Neuroscience and Society Summer School

#### Publications

Singh, I. (2004), "Doing their jobs: mothering with Ritalin in a culture of mother-blame", *Social Science and Medicine*, 59 (4), 1193-1205  
 Singh, I. (2004), ADHD. Dr. Albrecht's Encyclopedia of Disability. Sage Publications.  
 Singh, I. (forthcoming). Review of ADHD: The FACTS. Infant and Child Development.  
 Singh, I. (2005), "Will the 'real boy' please behave: Dosing dilemmas for parents of boys with ADHD", *American J. of Bioethics*, 5(3), 34-47.  
 Singh, I. (forthcoming). Not just naughty: 50 years of stimulant drug advertising. In A. Tone & E. Shorter (eds), *Medicating Modern America*. New York University Press

#### **Dr Claire Snowdon**

***Research Fellow, Medical Statistics Unit, Department of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine based in the Centre for Family Research.***

#### Research interests

##### *Psychosocial aspects of the new genetics*

Early work at the Centre for Family Research examined the attitudes of couples carrying recessive disorders to various reproductive options (adoption, parental diagnosis, gamete donation, pre-implantation diagnosis, informed consent and clinical trials).

##### *Views of participants in trials*

The original NPEU study involved qualitative analysis of interviews with around 80 parents of critically ill newborn babies enrolled in a clinical trial (The ECMO Trial). The research focused on parents' perceptions of the trial, the doctor-patient relationship, results of the trial and management of informed consent.

This work has been developed further as a research fellow at LSHTM, funded by the Nuffield Foundation through a study which involved approximately 120 interviews with staff and parents linked to two antenatal trials (TEAMS, ORACLE) and two neonatal trials (INNOVO, CANDA). Data were also collected for a related study in 2002, funded by Heartlink, which involved tape recording of informed consent procedures and follow up interviews with parents whose babies were included in a pre-trial study of the safety and feasibility of hypothermia and ECMO.

The most recent qualitative study was as part of an interdisciplinary collaboration, funded by MRC and HTA, with researchers from Aberdeen and Brighton universities, investigating factors and interventions associated with good and poor recruitment to multi-centre trials (STEPS) <http://www.abdn.ac.uk/hsru/hta/steps.shtml>. The collaboration involved three sub-studies; an epidemiological, a qualitative and a business theory approach. The qualitative study involved interviews with staff associated with four disparate trials in the areas of oncology, asthma management, mental health (anorexia nervosa) and cardiovascular care, and explored their views of the factors which had promoted or inhibited recruitment.

#### Current research

From October 2005-September 2007 I will continue to work on aspects of trial participation and collaboration as an ESRC/MRC Interdisciplinary Postdoctoral Fellow.

#### Recent publications

Snowdon, C., Elbourne, D. and Garcia, J. (2004), "Perinatal pathology in the context of a clinical trial: a review of the literature", *Arch Dis Child Fetal Neonatal Ed*, 89: F200-F203 [[full text](#)]

Snowdon, C., Elbourne, D. and Garcia, J. (2004), "Perinatal pathology in the context of a clinical trial: attitudes of neonatologists and pathologists", *Arch Dis Child Fetal Neonatal Ed*, 89:F204-F207. [[full text](#)]

Snowdon, C., Elbourne, D. and Garcia, J. (2004), "Perinatal pathology in the context of a clinical trial: attitudes of bereaved parents", *Arch Dis Child Fetal Neonatal Ed*, 89: F208-F211. [[full text](#)] See also Commentary by M. McDermott, The continuing decline of autopsies in clinical trials: is there any way back? *Arch Dis Child Fetal Neonatal Ed*, 89:F198-F199. [[full text](#)]

Snowdon, C., Elbourne, D., Garcia, J. (2004), "Embedding a qualitative approach within a quantitative framework: an example in a sensitive setting" in T. Lavender, G. Edwards, Z. Alfirevic (eds), *Demystifying Qualitative Research: A Resource Book for Midwives and Obstetricians*. Quay Books.

#### **Dr Bryn Williams-Jones**

My position as a post-doctoral fellow at the Centre for Family Research ended during the year and I took a contract position as Fellow in Ethics at Cardiff University to support the development of a research ethics infrastructure and promote a culture of ethics literacy across the university. I was successful in obtaining a permanent lecturing position back in Canada and have moved to Montreal to take up a post as Assistant Professor at the University of Montreal, teaching in the Bioethics Programmes.

#### Current Research

My research concerns university-industry relations and have put in an application to the Canadian Institute of Health Research to fund a pilot project on conflict of interest and

benefit-sharing. I have worked with Tabitha Freeman and Martin Richards on the social and ethical issues of paternity testing.

### Publications

Williams-Jones, B. (in press, 2005), “‘Be Ready Against Cancer, Now’: Direct-to-Consumer Advertising for Genetic Testing” *New Genetics & Society*.

Corrigan, O.P. & Williams-Jones, B. (in press, 2005), “Pharmacogenetics: the bioethical problem of DNA investment banking”, *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences*.

Reist, C., Albers, L.J., Marder, S.R., Williams-Jones, B., Wu, J.C., Mee, S., Shimoda, K., Someya, T. & Ozdemir, V. (in press, 2005), “A candidate pathway strategy for integration of pharmacogenomic components of variability in antipsychotic treatment outcomes: a focus on Aripiprazole” *Current Pharmacogenomics*.

Williams-Jones, B. & Burgess, M. (in press, 2005), “Democratising access to genetic services”, *Familial Cancer*, special issue on Oncogenetics: Achievements and Challenges.

Williams-Jones, B. & Ozdemir, V. (in press, 2005), “Enclosing the ‘knowledge commons’: patenting genes for disease risk and drug response at the university-industry interface” in C. Lenk, N. Hoppe & R. Andorno (eds), *Ethics and Law of Intellectual Property. Current Problems in Politics, Science and Technology*.

Williams-Jones, B. & Holm, S. (2005), “A university wide model for the ethical review of human subjects research”, *Research Ethics Review* 1(2), 39-44.

Williams-Jones, B. (2005), “Knowledge commons or economic engine – What’s a university for?” [Editorial], *Journal of Medical Ethics* 31(5), 249-250.

Burgess, M.M. & Williams-Jones, B. (2005), “Law in Tension with Evolving Ethical Perception: Prenatal Genetic Testing for Sex and Disability” Working Paper 71, Cardiff Institute of Society, Health and Ethics, School of Social Sciences, Cardiff University (ISBN 1 904815 37 5). (<http://www.cf.ac.uk/socsi/publications/workingpapers/pdf-files/wrkpaper-71.pdf>)

### **Dr Anji Wilson**

#### ***Research Associate***

Research interests include family and school-based support for children, family structure and genetic understanding; lay understanding of transplantation issues, individual differences in early childhood development.

September 2004 to the present I have been working with Dr Claire Hughes and her team on a longitudinal research project following the social development of a cohort of pre-school children.

## ASSOCIATE MEMBERS

**Dr Shelley Day Sclater (currently based in the Centre for Family Research.**

*Reader in Psychosocial Studies, Centre for Narrative Research, University of East London*

I am part-time Professor of Psychosocial Studies at the University of East London, a freelance writer and researcher, and a visiting scholar at the Centre for Family Research during 2005. I have a degree in Psychology (Edinburgh, 1979) and a PhD (Darwin College, Cambridge, 1985). I was a founder member of the Centre for Narrative Research at UeL. Formerly a family lawyer, I have taught and researched in law and psychology at various universities in Britain and abroad. I was co-founder, with Martin Richards and Andrew Bainham, of the Cambridge Socio-Legal Group. My main passion is all kinds of life writing and I am on the editorial board of the journal *Auto/biography* and an active member of the BSA *Auto/biography* Study Group. In 2005 I delivered the keynote speech entitled 'Something nasty in the woodshed? The cold comforts of *Auto/biography*' at the group's annual conference.

My research interests broadly include:

- Auto/biographies
- qualitative and narrative methodologies
- psychological and socio-legal studies of families and close relationships
- applications of psychoanalysis in social research
- theoretical work on subjectivities
- Current research activities include:
- Social capital and higher education project, with Prof. Claire Callender, ESRC Social Capital and Families Group, London Southbank University. I am currently analysing data from 90 qualitative interviews with university students.
- Family Advice and Information Services (FAInS) project, with Prof. Martin Richards, Centre for Family Research, colleagues at the Newcastle Centre for Family Studies, and Poppy Sclater, Children's Fund Participation Officer for Cambridgeshire. The project is funded by the Legal Services Commission. Our part of this larger project is 'Support for separating families: children's perspectives' and involves collecting qualitative data on children's experiences of parental separation and divorce, with a particular interest in the kinds of support that can benefit children and enhance their wellbeing.
- I am working on a book on selves and identities, based on personal narratives
- I am writing a chapter on close relationships for an Open University textbook

### Publications

M Andrews, S Day Sclater and C Squire and A Treacher (eds) (2004), *The Uses of Narrative: Explorations in Sociology, Psychology and Cultural Studies*, Piscataway, NJ, Transaction Publishers, Rutgers, The State University of New Jersey.

Andrews, M., Day Sclater, S., Squire, C. and Tamboukou, M. (2004), 'Stories of Narrative Research', in C. Seale, D. Silverman, J. Gubrium and G. Gobo (eds) *Qualitative Research Practice*, London, Sage.

Day Sclater, S. (2004), A Question of Origins: Shelley Day Sclater explains how the Chillingham Cattle helped Darwin with his theory of evolution by natural selection, *The Northumbrian* October/November 2004, p14-15 (1500 words)

Day Sclater, S. (2004), Review of *Divorcing Responsibly*, by Helen Reece, Hart, 264pp, ISBN: 1-84113-015-X, published September 2003, *THES* 13 February 2004, 600 words

Day Sclater, S. (2004), Review of *Therapeutic Dimensions of Autobiography in Creative Writing*, by Celia Hunt, 208pp, ISBN 1-85302-747-2, Jessica Kingsley, *Auto/biography* 12(2): 172-174

Day Sclater, S. (2004), Review of *Therapy Culture* by Frank Furedi, 245pp, ISBN 0-415-32159-X, Routledge, *The Psychologist* 17(6):343, 300 words

Day Sclater, S. (2004), 'Not just privation or adversity', Review of *Therapy Culture* by Frank Furedi, 245pp, ISBN 0-415-32159-X, Routledge, *Auto/biography* 12(3): 264-266, 1000 words

Day Sclater, S. (2005), 'The Troubles with Psychoanalysis...', *Auto/biography* (in press)

Kaganas, F. and Day Sclater, S. (2004), 'Contact Disputes: Narrative Constructions of Good Parents', 12 *Feminist Legal Studies* 1-27.

**Dr Andrew Bainham,**  
*Faculty of Law, University of Cambridge, Fellow of Christ's College*

**Dr. Fatemeh Ebtehaj**

**Dr Margaret Ely**  
*Anglia Polytechnic University.*

**Dr Judith Ennew**  
*Currently based in Bangkok.*

**Dr Nina Hallowell**  
*Lecturer in Social Sciences and Public Health, Public Health Sciences, The Medical School, University of Edinburgh*

**Ms Bridget Lindley**  
*Family Rights Group, London.*

**Professor Juliet Mitchell**  
*Faculty of Social and Political Sciences and Fellow of Jesus College*

**Dr Deborah Thom**  
*College Lecturer, Director of Studies in History and Tutor, Robinson College Cambridge*

## **VISITORS**

**Ms Serena Lecce**

Serena Lecce is a PhD Student from the University of Pavia. Her research interests are in developmental psychology and more specifically, in children's representations of their close

relationships (friendships and sibling relationships). She has spent time at the Centre as a visiting researcher, working with Dr Claire Hughes.

### **Dr Kerry Petersen**

Dr Kerry Petersen teaches medical law and torts at La Trobe University and the major focus her research has been on human reproduction law. She is co-editing "Disputes and Dilemmas in Health Law" (Federation Press) with Dr Ian Freckelton and while at the CFR conducted comparative research into the regulation of human reproduction for her chapter "Reproductive Health Law: Emerging Dilemmas" in the book. She also attended hearings at the House of Commons held by the Select Committee which has been appointed to review the regulation of the assisted reproductive technologies in the UK.

#### Recent publications

"Assisted reproductive technologies: professional and legal restrictions in Australian clinics", *Journal of Law and Medicine*, (forthcoming) (co-authors: G Baker, M Pitts & R Thorpe).

"The rights of donor-conceived children to know the identity of their donor: the problem of the known unknowns and the unknown unknowns" in B. Bennett and G. Tomossy (eds), *Globalisation and Health*, (Kluwer, 2004)(forthcoming).

"Abortion laws: comparative and feminist perspectives in Australia, England and the United States" in B. Bennett, *Abortion*, Ashgate: UK, 2004. (forthcoming) [Reprint].

"The sexual zone between childhood and the age of majority: claims to sexual freedoms versus protectionist policies" in B.M. Brooks-Gordon, L.R. Gelsthorpe, M.H. Johnson and A. Bainham. *Sexuality Repositioned: Diversity and the Law*, Hart Publishing: Oxford, 2004, 351-372.

### **Dr Helena Willén**

Dr Helen Willén from the Nordic School of Public Health visited several times during the year in connection with the collaborative study of couple's decision-making related to divorce.

### **Dr Jan Pryor**

Dr Jan Pryor visited us from New Zealand. She is the Director of the Roy McKenzie's Centre for the Study of Families at Wellington. We send our best wishes to this sister centre in the southern hemisphere.

### **Dr Silvana Santos**

Silvana Santos is a post-doctoral visiting researcher from the University of São Paulo, Brazil. Her interests are both in education and genetics. She has studied everyday ideas of inherited disorders in Brazilian families. She spent 5 months at the Centre working with Professor Martin Richards. She hopes to organize a collaboration to study the evolution of ideas to genetic disorders in a rural community of Brazil. How would the ideas inside a rural community change with introduction of new genetics information and genetic testing?

#### Grant held

Research Fellowship of the FAPESP ( Fundação de Amparo a Pesquisa do Estado de São Paulo) (Funded period – Setember 2005 – January – 2005).

### Publications

Kok, F., Santos, S., Amorin, S., Macedo-Souza, L.I., Starling, A., Zatz, M. (submitted), "Spastic paraplegia, optic atrophy and neuropathy: SOAP syndrome", *Annals of Neurology*.

Santos, S., Infante-Malachias, M.E., Amabis, J.M. (2004), "Estratégias meta cognitivas de aprendizaje en la planificación de una secuencia didáctica sobre digestión", *Journal of Science Education*, 5 (1), 24-27.

Santos, S. and Bizzo. (in press), "From new genetics to everyday knowledge: ideas about how genetic diseases are transmitted in two large Brazilian families", *Science Education*.

Koga, D., Santos, S., Infatante-Malachias, M.E., Amabis, J.M. (in press), La influencia de dos secuencias didácticas sobre la construcción de narraciones de los estudiantes de enseñanza básica: un ejemplo sobre el tema electricidad, *Journal of Science Education*.

## **INTEREST GROUPS AND WORKSHOPS**

### **Cambridge Genetics Group**

The Group has had a regular series of seminars through the 3 terms of the academic year organised by Drs Oonagh Corrigan and Bryn Williams-Jones. Seminar speakers have come from Cambridge and more widely and we have been able to take advantage of the presence of a number of overseas visitors in Cambridge to invite them to give seminars. Members of the Group are drawn from a wide variety of institutions in Cambridge including the Centre for Family Research, History and Philosophy of Science, Social Anthropology, Law, Public Health, Medical Genetics and Public Health Genetics.

The Group's activities have received financial support from the Cambridge Genetic Knowledge Park.

The Group is open to anyone interested in social science and ELSI research related to genetics and genomics. Anyone wishing to be on our email mailing list should contact one of the organisers

Martin Richards

### **Cambridge Body Research Group**

The Cambridge Body Research Group began in 1999 as an interdisciplinary group drawing heavily from recent interest in the sociology and anthropology of the body. It continues to organise a full programme of seminars during term time coordinated by Professor Bryan Turner, Dr Darin Weinberg and Shirlene Badger. During the past academic year we have conducted discussions of key articles in the area and hosted Professor Margaret Lock from McGill University, Canada. We also hosted a farewell mini-conference for Professor Bryan Turner on 19 January 2005 'Body and Society: Contemporary Themes and Future Prospects' as a celebration of his contribution to the sociology of the body.

Shirlene Badger

Shirlene Badger

From October 2005 the Genetics and Body Groups, together with colleagues from Social Anthropology and the Department of History and Philosophy of Science will organise a joint series of seminars concerned with social bodies, reproduction and genetics, "The Free School Lane Seminars". These will be arranged by Shirlene Badger, Nick Hopwood, Maryon MacDonald, Martin Richards and Susan Wallace. Anyone wishing to join the email distribution list for information about these seminars should contact the CFR Administrative Secretary ([cfr-admin@lists.cam.ac.uk](mailto:cfr-admin@lists.cam.ac.uk)).

### **The Brazelton Centre**

#### ***Activities of the Brazelton Centre in Great Britain 2004-2005***

Work at the Brazelton Centre focuses on promoting healthy parent-infant relationships. Through conferences and workshops aimed at health professionals, information about infant behaviour and development and assessment, and parent-infant relationships are presented. The Centre was opened in 1997 and so far has trained 55 health professionals in the Neonatal Behavioural Assessment Scale (NBAS), and has 65 people in the process of training. The Centre is a charity with three trustees and 6 co-founders. The NBAS has been used with newborns in research and as a supportive intervention in 700 studies worldwide. Johnson and Johnson funded the Centre in 1997-1998 and a conference in Cambridge in 1997. The Johnson and Johnson Pediatric Institute funded a conference in London in 2004 with Dr. T. Berry Brazelton and Dr. Kevin Nugent as keynote speakers. Almost 400 people attended. A video called "More than Words can Say" about infant behaviour was also funded. The conference generated interest in training, and health professionals from 6 Sure Start areas in the UK are training, including Cambridge. Nurses and a Consultant neonatologist at the Rosie Hospital, Addenbrookes in Cambridge are also in training, as are nurses in other UK hospitals. Johnson and Johnson in Poland are funding up to 15 nurses to be trained in the NBAS, and presentations were made to the Polish Neonatal Society in November, 2004 and the Polish Paediatric Nurses Association in October, 2005. Media interest has involved sessions on Woman's Hour, breakfast television, and Radio 4. The new Baby Channel on Sky TV is making arrangements to feature the work of the Brazelton Centre. Workshops, training and conferences are advertised in professional journals. A Study Day was held in Middlesbrough in February, 2005 with 80 health professionals attending, and at the next Study Day in Cambridge in March, 2006, Dr. Kevin Nugent from the Brazelton Institute, Boston will be the keynote speaker. For information: [www.brazelton.co.uk](http://www.brazelton.co.uk)  
Coordinator and trainer: Dr. Joanna Hawthorne, 01223-245791

### **Infant Relationships Study Group**

This group meets termly for seminars, discussion and presentations on parent-infant relationships and infant mental health issues. It aims to include academics, health professionals and volunteers who work with infants. Several members of this group are also involved in the founding of CAMPIP, the Cambridge Parent-Infant Project, an infant mental health service in Cambridge. Joint presentations are organised.

Joanna Hawthorne



**Cambridge Socio-Legal Group****The Group's current and recent seminars****Kin and Care**

A seminar on Kin and Care which took place in September 2005 was organised by Bridget Lindly, Fatemeh Ebtehaj, Michael Lamb and Martin Richards. As with previous projects the papers discussed at this meeting are being revised and edited for a book which will be published in 2006.

**Forthcoming Projects**

The Group is taking forward a project on the subject of 'Death'. It is expected that the seminars for this project will take place in September, 2006.

The Group has also organised occasional seminars and lectures throughout the year.

## CENTRE FOR FAMILY RESEARCH

### LUNCHTIME SEMINARS – MICHAELMAS TERM 2004

(Meetings are held at 1.00 p.m. on Tuesdays - normally in Room 606, CFR. .

Please note that the seminar on the **26<sup>th</sup> of October** will be held in **Room B-16 in the Law Faculty, West Road, to allow for disabled access**)

**12<sup>th</sup> October**

**Dr Tabitha Freeman**

(Centre for Family Research, University of Cambridge)

*Changing Fathers, Changing History: an evaluation of historical narratives of fatherhood*

**26<sup>th</sup> October**

**ROOM B-16  
LAW FACULTY**

**Michele Wates**

Disabled Parents Network research liaison, DPN Handbook Coordinator)

*Disabled Parents: Righting the Family Picture*

**9<sup>th</sup> November**

**Dr. Felicia Huppert**

(Cambridge Interdisciplinary Research Centre on Aging, University of Cambridge)

*Positive aging*

**23<sup>rd</sup> November**

**Christine Rogers**

(Centre for Family Research)

*Parenting children with educational impairments : qualitative research*

**PLEASE NOTE THAT ALL SEMINARS BEGIN PROMPTLY**

**AT 1 p.m.**

Centre for Family Research, University of Cambridge, Free School Lane, Cambridge  
CB2 3RF Tel: (01223) 334510

## CENTRE FOR FAMILY RESEARCH

### LUNCHTIME SEMINARS – LENT TERM 2005

Meetings are held at 1.00 p.m. on Tuesdays in Room 606  
All welcome

**25<sup>th</sup> January**

**Dr Lucy Howell & Dr Srikant Sarangi**  
(Health Communication Research Centre, Cardiff University)

*Responsible familial selves: socio-moral and psychological reasoning in genetic counselling discourse.*

**15<sup>th</sup> February**

**Dr Marcus Redley**  
(Developmental Psychiatry, University of Cambridge)

*Self-advocacy: an exploratory video study in face-to-face communication between people with learning difficulties and service providers.*

**1<sup>st</sup> March**

**Dr Sally Sheldon**  
(Department of Law, Keele University)

*Fatherhood and the regulation of reproductive technologies.*

**15<sup>th</sup> March**

**Dr Shobita Parthasarathy**  
(Center for Society and Genetics, University of California, Los Angeles & Centre for Family Research, University of Cambridge)

*Genomic medicine in transnational context: between the UK and Europe.*

**PLEASE NOTE THAT ALL SEMINARS BEGIN PROMPTLY  
AT 1 p.m.**

Centre for Family Research, University of Cambridge, Free School Lane, Cambridge  
CB2 3RF Tel: (01223) 334510





## CENTRE FOR FAMILY RESEARCH

**LUNCHTIME SEMINARS – EASTER TERM 2005**  
Meetings are held at 1.00 p.m. on Tuesdays in Room 606  
All welcome

**17<sup>th</sup> May**

**Rosie Ensor**

(Centre for Family Research, University of Cambridge)

*Young children's social competence: Associations with 2-year-olds' socio-cognitive skills and relationships with caregivers.*

**14<sup>th</sup> June**

**Clare Williams**

(Dept of Midwifery and Women's Health, King's College, London)

*Framing the fetus in medical work: representations and practices.*

**PLEASE NOTE THAT ALL SEMINARS BEGIN PROMPTLY  
AT 1 p.m.**

Centre for Family Research, University of Cambridge, Free School Lane, Cambridge  
CB2 3RF Tel: (01223) 334510