

# **CENTRE FOR FAMILY RESEARCH**

## **ANNUAL REPORT (Academic Year 2002 – 2003)**

**Director of Centre  
Professor Martin Richards**

**Deputy Director  
Ms Helen Statham**

### **Members of the Centre**

#### **Research Staff and Post-Graduate Students\***

Dr Anna Bagnoli  
Dr Elizabeth Chapman  
Dr Oonagh Corrigan  
Ms Rosie Davie\*  
Dr Claudia Downing  
Dr Fatemeh Ebtehaj  
Dr Judith Ennew  
Dr Gail Ewing  
Georgina Haarhoff\*  
Dr Joanna Hawthorne  
Dr Claire Hughes

Dr Antonella Invernizzi  
Dr Julie Jessop  
Dr Lynne Jones  
Bridget Lindley  
Ms Rachel Marfleet  
Dr Shobita Parthasarathy  
Maggie Ponder  
Dr Ilina Singh  
Claire Snowdon  
Dr Bryn Williams-Jones  
Dr Anji Wilson

#### **Associate Members**

Lucy Allcock\*  
Dr Andrew Bainham  
Dr Shelley Day Sclater  
Margaret Ely  
Dr Nina Hallowell  
Eva Lloyd

Prof Juliet Mitchell  
Frances Murton  
Dr Thelma Quince  
Dr Eileen Richardson  
Dr Deborah Thom  
Dr. Jane Weaver

Launching Children and their Families:  
Contact, Rights and Welfare” at the  
Nuffield Foundation, London.

11<sup>th</sup> September 2003



### Visitors

Professor Ann Robertson (October - June) University of Toronto

Professor Ben Bradley (June - September) Charles Sturt University, NSW

Dr Elvidina Adamson-Macedo (February - March) University of Wolverhampton

Dr Helena Willén (July) Nordic School of Public Health, Göteborg

Silvana Santos (January - February) University of Saõ Paulo

Dr Alice Wexler (October 2002) - University of California and Hereditary Disease  
Foundation

Serena Lecce (January - August) University of Pavia

Michelle Byrne (June - September) University of Chicago

Yee San Teoh (June - July) University of Durham

**New Members of the Centre 2003-2004**  
Ms Shirlene Badger\*

**Assistant Staff**

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

**Management Committee**

Professor Ian Goodyer (Chair until May 2002 and from December 2003, Division of Developmental Psychiatry, University of Cambridge)

Professor Tony Manstead (Acting Chair from June 2002 to November 2003, Faculty of Social and Political Sciences)

Ms Erica de'Ath (National Council for Voluntary Child Care Organisations, London)

Dr Mavis Maclean (Centre for Family Law and Policy, University of Oxford)

Professor Martin Richards

Dr Jacqueline Scott (Social and Political Sciences Faculty)

Ms Helen Statham

Professor Bryan Turner (Social and Political Sciences Faculty)

Ms Kate Stacey (Secretary)

Dr Darren Weinberg (Social and Political Sciences Faculty)

**Joiners and Leavers**

**Dr Oonagh Corrigan** joined the Centre in October 2002 following her appointment as a lecturer in the Cambridge Genetic Knowledge Park. Under the arrangements for the Knowledge Park 60% of her time is spent in the Centre, the remainder with the Knowledge Park which is based in the Strangeways laboratories.

We welcome a new post-doctoral fellow to the Centre - **Bryn William-Jones** from the Centre for Applied Ethics at the University of British Columbia. Bryn has joined us to work on social, ethical, and policy issues arising with the commercialisation of biotechnology, in areas such as university-industry relations, genetic testing and intellectual property rights, and pharmacogenetics. He is supported by a Social Sciences and Humanities Research Council of Canada fellowship, and is a junior research fellow at Homerton College.

**Shobita Parthasarathy** is a post-doctoral fellow who did her Ph.D. at Cornell University in their Sociology of Science and Technology Program. Together with Martin Richards she was awarded a Wellcome Trust Fellowship for work on the globalisation of genetic technologies.

**Shirlene Badger** joined the Centre in September 2003 as a Wellcome Trust funded PhD student. Her project is entitled "A genetic diagnosis for obesity: social and moral experiences of the body and responsibility in childhood" and she will be supervised by Oonagh Corrigan and Martin Richards.

**Anna Bagnoli** completed her ESRC Post doctoral Fellowship in June 2003 and is taking up a Research Fellow position at ISET, the Institute for the Study of European Transformations, at

London Metropolitan University. Anna, who had previously completed her Ph.D. on 'Narratives of Identity and Migration: an Autobiographical Study on Young People in England and Italy' in the Centre will continue to have a link with us as an Associate Member.

In May **Dr Ann Robertson** completed her study of bioethics and genetics funded by a Career Transition Award from the Canadian Institutes of Health Research (CIHR) Institute of Genetics. Dr Robertson returned to her position as Associate Professor in Social Science and Health in the Department of Public Health Sciences, Faculty of Medicine, University of Toronto.

Two student volunteers completed research placements during the summer of 2003 working with Claire Hughes on the Toddlers Up! project: **Michelle Byrne**, from the University of Chicago, and **Yee San Teoh**, from the University of Durham.

**Georgina Haarhoff** was a member of the Centre for Family Research until June 2003. She completed her PhD in May 2003 and has joined the Civil Service and has a post in the Treasury.

We also congratulate **Fatemeh Ebtahaj** on the award of her Ph.D. (Co-constructing selves: Iranian exile women and midlife development). Fatemeh is now writing a book related to her Ph.D. work.

**Jane Weaver** left the Centre after 3 years in October 2002 to take up a post as a Lecturer in Midwifery at Thames Valley University. She maintains her links with the Centre as an Associate Member through ongoing work on caesarean sections with Helen Statham.

## RESEARCH OF MEMBERS OF THE CENTRE

### **Professor Martin Richards – Director**

*Professor of Family Research, Faculty of Social and Political Sciences*

*A review of interventions and support services for children experiencing parental divorce and other major family change (with Dr Jan Pryor, Division of Psychology, Victoria University of Wellington, New Zealand, Dr Joanna Hawthorne and Dr Julie Jessop). Funded by the Joseph Rowntree Foundation. 2000 - 2003.*

This project provides a review of services directed at children. The work has been completed and the report was published earlier in the year. The Joseph Rowntree Foundation is planning a series of dissemination activities and events for this and related projects on family change.

*Understanding inheritance and kinship connection (with Dr Anji Wilson). Funded by The Wellcome Trust. 2000 - 2003.*

This qualitative study explores connections between everyday knowledge of inheritance and concepts of kinship and family obligation. Qualitative interviews with samples of young people and recent parents are being analysed and the work is being prepared for publication.

*Non-disclosure of genetic risk information (with Dr Angus Clarke, University of Cardiff and Lauren Kerzin-Storror, N.W. Regional Genetics Service and other collaborators). 2000 - 2004.*

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. The work is now in the final stages and is being written up for publication.

*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 study is 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 appointed to the project is Dr Neil Manson.

#### **Research based outside Cambridge**

I am involved in the following collaborative projects:-

The Basque Government and University of the Basque Country. Family interaction and psychological development of 5 year old Basque children (with Enrique Arranz. Euskal Herriko Unibertsitatea).

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

Canadian Institute of Health Research. Ethics of Health Research and Policy. 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.

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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.

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I am a member of the Management Committee of the (Cambridge) Centre for Medical Genetics and Policy and on the Advisory Board for the Cambridge Genetic Knowledge Park.

I have served on the Nuffield Council on Bioethics working party on genes and Behaviour. The report 'Genes and Behaviour: The ethical context' was published in October 2002.

Papers related to this work have been presented at a number of national and international meetings.

The final stages of editorial work (with Jackie Scott and Judy Treas) for the Blackwell Companion on Sociology of the Family has been completed. The book will be published in November 2003.

I am a member of The Wellcome Trust Biomedical Ethics Panel.

During the year I completed my second and final 3-year term as external examiner for the M.Sc. in Genetic Counselling at the University of Manchester.

I have been reappointed to the Human Genetic Commission for a further 3-year term. I am the lead person on Biobank UK and Genetic data base research and I co-chair a new working party on Reproductive Choice and Genetics and am involved in preparing a report on relationship genetic testing.

#### Publications

Bainham, A., Lindley, B., Richards, M.P.M. and Trinder, L. (eds) (2003), *Children and their Families: Contact, Rights and Welfare*, Oxford, Hart.

Richards, M.P.M. (2003), "Assisted reproduction and parental relationships", in A. Bainham, B. Lindley, M.P.M. Richards, and L. Trinder, (eds) (2003), *Children and their Families: Contact, Rights and Welfare*, Oxford, Hart.

Hawthorne, J., Jessop, J., Pryor, J. and Richards, M. (2003), (eds) "Supporting Children Through Family Change: A Review of Interventions and Support Services for Children of Divorcing and Separating Parents", York: YPS/Joseph Rowntree Foundation.

(Co-author/member of Working Party) (2003), "Genetics and Human Behaviour: The ethical context", London: Nuffield Council on Bioethics.

Richards, M.P.M., Ponder, M., Pharoah, P., Everest, S. and Mackay, J. (2003), "Issues of consent and feedback in a genetic epidemiological study of women with breast cancer", *J. Medical Ethics*, 29, 93-96.

Richards, M.P.M. (2003), "Lay understanding of heredity", in *The Encyclopedia of the Human Genome*, Nature Publications.

#### In press

Richards, M.P.M., Scott, J. and Treas, J.K. (2003), (eds) *Blackwell Companion to the Sociology of Families*, Blackwell.

Richards, M.P.M. (2003), "Assisted reproduction, genetic technologies and family life", in J. Scott, J. Treas and M. Richards (eds), *Blackwell Companion to the Sociology of Families*, Blackwell.

Richards, M.P.M. (2003), "Attitudes to genetic research and uses of genetic information: support, concerns and genetic discrimination", in B.M. Knoppers (ed), *Population and Genetics: Legal Socio-Ethical Perspective*, Kluwer Legal International.

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

Richards, M.P.M. (2003), "DNA families, *Biological Sciences Review*.

Richards, M.P.M. (2003), "Loitering with intent in a special care baby unit", in J. Lawton, S. Gregory and N. Hallowell (eds), *Reflections upon Research: The Perils, Pitfalls and Pleasures of Doing Social Science Research*, Open University Press.

## **Ms Helen Statham**

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

#### Current research

***Psychosocial effects of molecular genetic diagnosis: the case of X-linked learning disability, Genetics of Learning Disability (GOLD) Study – Grant holders are Martin Richards, Lucy Raymond and Nina Hallowell; Maggie Ponder is a co-worker on the study .The study began recruiting participants in April 2003 and will continue until February 2007.***

In 2002 the Wellcome Trust agreed to fund a longitudinal study - *Psychosocial effects of molecular genetic diagnosis: the case of X-linked learning disability* – 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 psychosocial study examines the beliefs, understandings, attitudes and behaviours of family members before and after genetic testing. Specifically, the study will explore and document:

- aspects of family life when one or more family members has a learning disability
- parents', normal siblings' and (where possible) affected boys'/men's' perceptions of the disorder before and after a gene abnormality is identified, and the possible changes in family relationships
- the ways in which information about the disorder is communicated within families and actions that may follow the receipt of information about the genetic basis of the disorder.
- attitudes towards the GOLD Study and perceptions of the possible benefits or complications of developments in genetic testing for families.

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Although previous research studies investigating psychological, social and service implications of prenatal diagnosis (with Jo Green, University of Leeds and Wendy Solomou, now at Dept of Land Economy, Cambridge) and decision-making around caesarean section (with Jane Weaver, now at Thames Valley University) are completed, further analysis of the wealth of data is ongoing. Further collaborative work on the emotional well being of teenage mothers is planned with Elvidina N Adamson-Macedo and David Sallah of the University of Wolverhampton.

#### Publications

Statham, H. (2002), "Prenatal diagnosis of fetal abnormality: the decision to terminate the pregnancy and the psychological consequences", *Fetal and Maternal Medicine Review*, 13, 213 – 247.

Statham, H. (2003), "The parents' reactions to termination of pregnancy for fetal abnormality: from a mother's point of view", in L. Abramsky and J. Chapple (eds), *Prenatal Diagnosis: the human side*, pp 182 – 196, Nelson Thornes (2<sup>nd</sup> Edition).

Statham, H., Solomou, W. and Green, J.M. (2003), "Continuing a pregnancy after the diagnosis of an anomaly: parents' experiences", in L. Abramsky and J. Chapple (eds), *Prenatal Diagnosis: the human side*, pp 164 – 176, Nelson Thornes (2<sup>nd</sup> Edition)

Statham, H., Solomou, W. and Green, J.M. (2003), "Communication of prenatal screening and diagnosis results to community health professionals", *Public Health*, 117, 348 –357.

#### In press

Green, J.M., Kafetsios, K., Statham, H.E. and Snowdon, C.M. (2003) "Factor structure, validity and reliability of the Cambridge Worry Scale in a pregnant population", *Journal of Health Psychology*, 8(6).

#### Invited lectures

*The who, how and why of information transfer: implications for parents and health professionals.* Invited Speaker, Annual Anglian Regional Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) conference, November 2002.

*Communicating about prenatal test results between hospitals and primary care.* Invited lecturer, the Alan Bibby Memorial Lecture, Royal College of General Practitioners (RCGP), North Eastern Region, April 2003.

#### Other activities

Member of the Advisory Body of the ESRC-funded Innovative Health Technology Project: *Social implications of one-stop first trimester prenatal screening.*

Dissemination of findings of previous studies on prenatal screening and diagnosis to midwifery and other health professionals, and to inform national committees including the UK National Screening Committee and the Human Genetics Commission.

Continuing work with the voluntary sector group Antenatal Results and Choices (ARC) to translate research findings into practice. In particular, findings from the recent NHS funded study *When a baby has an abnormality: a study of parents' experiences* (Statham, H., Solomou, W., Green, J.M.) informed the recent publication by ARC 'Supporting you throughout your pregnancy: a handbook after a prenatal diagnosis'.

### **Anna Bagnoli**

*ESRC Postdoctoral Fellowship, July 2002 - June 2003*

#### List of activities:

Dissemination of PhD research.

Undergraduate supervisions in ethics of social research for the INT1 'Inquiry and Analysis' paper of the Social and Political Sciences Tripos.

Refereeing for *Modern Italy* journal.

Piloting of visual approaches to the study of migrant identities, making use of photography as a tool to narrate identities and the experience of migration.

#### Expert consultancy

Council of Europe and European Commission Research Partnership, Consultation with Researchers on the New Generation Youth Programme, European Youth Centre, Budapest, 8-9 July (invited expert).



Conference Papers - As invited speaker:

Council of Europe Research Seminar 'Resituating Culture: Reflections on Diversity, Racism, Gender and Identity in the Context of Youth', European Youth Centre, Budapest, 10-15 June 2003. A. Bagnoli, *Constructing the hybrid identities of Europeans*.

Media dissemination

Interviewed by BBC radio 4 for the programme 'Thinking Allowed' on the themes presented in the paper *Between outcast and outsider: Constructing the identity of the foreigner* at the Annual BSA Conference 'Social Futures: Desire, Excess and Waste', University of York, April 11-13, 2003. The programme has yet to be broadcast.

Publications

Bagnoli, A. (2003), "Imagining the Lost Other: the Experience of Loss and the Process of Identity Construction in Young People", *Journal of Youth Studies*, 6(2), 203-217.

Bagnoli, A. (2002) "Self-portrait as a young person: an autobiographical project on the identities of young people in England and Italy", final report distributed to research participants.

Bagnoli, A. (2002) "The Identities of Young People in Europe. A Research on the Process of Identity Construction among European Young People: Suggestions for Policies, and the EC 'White Paper on Youth'". STOA Briefing Note n. 513/2002 EN, PE n. 311.198, publication of the European Parliament.

In press

Bagnoli, A. "Researching identities with multi-method autobiographies". *Sociological Research Online*.

**Elizabeth Chapman**

In the last year I have been involved in a number of different activities and initiatives in my role as Research Facilitator for the Council of the School of Humanities and Social Sciences (CSHSS), and also started working on a number of new research projects in palliative care and pain.

**Research Facilitator, CSHSS, University (part-time).**

**Grant for Research through Centre for Family Research from Papworth NHS Trust  
January 2002 – December 2003 – renewing annually**

**Research Associate – Cystic Fibrosis Centre, Papworth Hospital (part-time).**

Working on:

- 1 Support for people with CF receiving palliative care, their relatives, and the staff; creating A Model of Good Practice (to be presented at the North American CF Conference in Anaheim, October 2003).
- 2 Family Support for people with Cystic Fibrosis – what do the patients want? (to be presented at the North American CF Conference in Anaheim, October 2003).
- 3 Transplantation in end stage Cystic Fibrosis.

**Grant for Research through Centre for Family Research – from Arthur Rank House – May 2003 renewing annually.**

**Research Associate – Arthur Rank Hospice, Cambridge. (Part-time)**

Working with the multidisciplinary pain group.

Conference presentation

BSA Medical Sociology Group, September 2001, York, “Transplantation in Cystic Fibrosis: Donation, Acceptance, and Rejection”.

Associate Editor

Body Image: An International Journal of Research, Elsevier Science.

Publications

Chapman, E. (2002), “Difficult Decisions: The Social and Ethical Implications of Advances in Medical Technology”, *Community Genetics*, 5(2), 110-119.

**Oonagh Corrigan**

*Centre for Family Research, SPS and Cambridge Genetics Knowledge Park*

*‘The socio-cultural and ethical implications of innovative genetics-based drug development: A case study of pharmacogenetics.’ Funded by The Wellcome Trust (Biomedical Ethics Programme). April 2000 to September 2003.*

This study examining the social and ethical aspects of developments in pharmacogenetics, focusing on the ethical frameworks being utilised by the industry and other key actors in the field, is now completed. Findings reveal a number of contradictory and problematic issues surrounding ‘informed consent’ for the collection of DNA samples during clinical drug trials. These findings suggest that the limits of informed are being over-stretched. The study also reveals the ways the rhetoric of ‘hope, hype and fear’ shapes understanding and propels developments in this field.

Teaching and editorial work

During my first year in post I have undertaken a number of teaching activities. These include; supervision and examination marking for the ‘Medicine, body and society’ (INT 3) paper, seminars for medical anthropology as well as taking part in various CGKP (Cambridge Genetics Knowledge) Park presentations and initiatives. Together with Richard Tutton I have also submitted an edited volume on the social and ethical aspects of population DNA databanks to be published by Routledge, due out in May 2004.

Publications

Corrigan, O. P. and Williams-Jones, B (2003), “Consent is not enough —putting patients first in clinical trials”, *Lancet*, 361, 2096-2097.

Corrigan, O. P. (2003), “The limitations of current ethical regulations”, in J. Abraham, A. Towse and H. Lawton-Smith (eds), *Regulation of the Pharmaceutical Industry*, pp. 195-211, London: Palgrave.

Corrigan, O. P. (2002), “‘First in man’: the politics and ethics of women in clinical drug trials”, *Feminist Review*, 72, 40-52.

In Press

Corrigan, O. P. (2003), "Empty ethics: the problem with informed consent", *Sociology of Health and Illness*.

Williams-Jones, B and Corrigan, O. (2003), "Rhetoric and hype: where's the "ethics" in pharmacogenomics?", *American Journal of Pharmacogenomics*.

Papers Presented

Corrigan, O. P. (2003) "Bioethics and drugs: protecting patients and facilitating research", Paper presented, CBA (Comparative Studies in Biotechnology and Accountability) Workshop. Girton College, Cambridge, 31st May 2003.

Corrigan, O. P. (2003) "Informed consent in Pharmacogenomics Research", Paper presented: Wales-Cambridge Social Science and Genetics Symposium, University of Wales, 30th April 2003.

**Rosie Davie***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*

Framed within a larger study of a sample of 140 toddlers who are at-risk of developing behaviour problems, the overall aim of my Ph.D. work is to examine the association between caregiver-toddler positive interactions and the expression and stability of problem behaviours. The main body of my Ph.D. work is based on observations within homes and in more structured settings, and aims to explore whether disadvantaged toddlers experience significant differences in their positive interactions with caregivers.

Other Activities.

During the last academic year I supervised first year students taking Social Psychology, and second year students taking Experimental Psychology courses.

**Claudia Downing**

*Wellcome Trust Research Fellow in Biomedical Ethics (Jan 2002 – December 2004)*

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.

***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.

Conference and seminar presentations

4<sup>th</sup> International Myotonic Dystrophy Consortium Meeting. Glasgow, April 2003: Parenting in the face of a late-onset genetic disorder: a comparative study of parents facing either Myotonic Dystrophy (DM) or Huntington's disease (HD).

World Congress on Huntington's Disease, Toronto August 2003. Invited paper: Reproductive Decision-making in two generations of Families facing HD in the UK: conceptions of responsibility, but the conference was subsequently cancelled due to power failures in Canada .

Using NUD\*IST to unveil the model of responsibility: how excess became less and revealed more, to the Qualitative Research Group, at the QSR headquarters in Melbourne, Australia, November, 2002. April, 2003: Parenting in the space between health and illness: some preliminary findings from a study of parents facing a late-onset genetic disease, Huntington's disease or Myotonic Dystrophy, the Centre for Applied Ethics, University of British Columbia, Vancouver.

I presented my PhD and current work at the HD Update Meeting at Addenbrookes Hospital in March 2003, and at the Cambridge Cardiff Genetic Group meeting held in Gregynog May 2003.

Teaching:

I was invited to lecture on decision-making in the face of genetic risk for the Public Health Science Module 2 which forms part of the masters programme at the Nordic School of Public Health in Gothenberg, April 2003.

**Dr Fatemeh Ebtehaj**Research interests:

Gender related issues; psychological development, especially issues related to exile and/or immigration; narrative and cultural psychology; discourse analysis.

Current research:

My PhD research focused on Iranian exile women at midlife. I am currently drawing on it to write articles in journals concerned with gender and exile, and with methodological issues in qualitative research. I am also extending my research to women of other generations with two research projects, a longitudinal study of second generation Iranian immigrants, and a study of Iranian immigrant women seventy years old and above.

**Dr Judith Ennew**

*Contact person for Childwatch International, attended Childwatch International Key Institution Meeting, December 2002, Bangkok, Thailand, on behalf of the Centre for Family Research.*

Teaching/research

- a) Technical Advisor and trainer for UNICEF Bosnia and Herzegovina, Capacity-building research on children in institutions; April-December 2002 (Report published in Sarajevo, July 2003)
- b) Technical Advisor and trainer, UNICEF India, March 2003, research methods and research design for studies of children in need of special protection measures;
- c) Technical Advisor and trainer for UNICEF Indonesia; Capacity-building research on child labour and child commercial sex workers. August 2002-August 2003; (Reports to be published in Jakarta, 2003);
- d) Social Protection Facility (Australian National University with Mahidol University); Academic Advisor on planning programmes for vulnerable children, Indonesia, Philippines, Thailand and Viet Nam.

Editorial

Editorial advisor, Regional Working Group on Child Labour (Bangkok, Thailand).

Advisor; Open University, Faculty of Education and Language Studies, course U212 'Childhood 0-18'.

Editorial Board: *Children's Geographies*.

International Editorial Board: *Childhood*.

Published interview

Meinert, L. and Valentin, K. (2003), "Some reflections on children, development and academia: An interview with Judith Ennew", *Anthropology in Action: Journal for Applied Anthropology in Policy and Practice*, 10 (1): 42-47.

Invited lectures/papers

Ennew, J. (2003), "Prisoners of childhood: orphans, institutionalisation and the construction of dependency", Paper for seminar and doctoral course, fifth seminar in the series on

Childhood – *Agency, Culture, Society: Institutionalisation, Individualisation, Agency*, Norwegian Centre for Child Research, University of Trondheim, Norway, 3-4 April 2003.

Ennew, J. (2003), “Beyond the country strategy papers: Wider perspectives”, Social Protection Facility Forum on Social Protection for Vulnerable Children, Mahidol University, Bangkok, Thailand, 27 June, 2003.

Ennew, J., Myers, W.E., and Plateau, D.P. (2003), “The meaning, nature and scope of child labor”, International Colloquium on ‘Using the Human Rights Framework to Combat Abusive Child Labor’, University of Iowa Center for Human Rights, 8-10 July, 2003.

#### Keynote addresses

“Children’s participation: experiences and reflections”, International Workshop on Child Participation Action, Beijing, China, 24-27 October, 2002, organised by the All China Federation of Women and Save the Children UK, (published in China in Chinese).

“Overview of the status of street children in the region”, A Civil Society Forum for South East Asia, Bangkok, Thailand, 12-14 March 2003, organised by UK Consortium for Street Children (published in the UK in Forum Proceedings).

#### Publication

Ennew, J. and Swart-Kruger, J. (2003), “Introduction: homes, places and spaces in the construction of street children and street youth”, *Children, Youth Environment*, 13 (2). <http://cye.colorado.edu>

### **Georgina Haarhoff**

#### ***Ph.D. Student***

Georgina finalised her thesis entitled ‘The Influence of Social Stigma and Personal Cancer Experience on Decision-Making in People affected with an Inherited form of Colorectal Cancer’ in May 2003. This was an ESRC-funded project supervised by Professor Martin Richards and Professor Bryan Turner. This concluded that both stigma and a cancer experience frame the choices that people in hereditary bowel cancer families make about colorectal screening, disclosure of inherited risk information to other family members, and mutation searching. These findings have yet to be published.

### **Joanna Hawthorne**

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

***Foretelling Futures: Dilemmas in Neonatal Neurology (with Professor Priscilla Alderson, Margaret Killen, Inga Warren and Dr. John Wyatt, London). Funded by the Wellcome Trust. March 2002-March 2004.***

A social research project in four neonatal units interviewing parents and staff, about information sharing and uncertainty about the future development of the baby. The baby’s contribution and neurobehavioural responses to neonatal care are examined in two of the units.

### Publications

Hawthorne, J. (2002), "Follow-up of babies from a neonatal unit using the Brazelton Neonatal Behavioural Assessment Scale (NBAS)", *Journal of Reproductive and Infant Psychology* 20(3), 191.

Hawthorne, J. (2002), "Understanding the language of babies", in J. Raphael-Leff (ed), *Where the Wild Things Are*, London: Whurr.

Hawthorne, J., Jessop, J., Pryor J., and Richards, M. (2003), "Supporting children through family change: A review of interventions and services for children of divorcing and separating parents", York:YPS/Joseph Rowntree Foundation.

### In press

Hawthorne, J.T. (2003), "Psychological Aspects of Neonatal Care", in J.M. Rennie (ed), *Textbook of Neonatology*, 4th edition. London: Churchill Livingstone.

### Presentations and posters

Alderson, P., Hawthorne, J., Killen, M. and Warren, I. (2003), "Foretelling Futures: Dilemmas in Neonatal Neurology: A social research project in four NICUs", The Infant Development in Neonatal Intensive Care Conference, London.

Hawthorne, J., Alderson, P., Killen, M. and Warren, I. (2003), "Foretelling Futures: Dilemmas in Neonatal Neurology." Poster presented at the Society for Reproductive and Infant Psychology Conference, Dundee 2003. Abstract in *Journal of Reproductive and Infant Psychology* 21(3), 253-254.

Killen, M., Alderson, P., Hawthorne, J. and Warren, I. (2003), "Researching interpretations of care in neonatal units. Foretelling futures: Dilemmas in Neonatal Neurology." Paper presented at Medical Sociology Conference, York.

### Other activities

Coordinator of the Brazelton Centre in Great Britain (registered charity number 1086814) which aims to promote an understanding of infant behaviour, and foster strong parent-infant relationships through research, and training for health professionals in the Neonatal Behavioural Assessment Scale (NBAS):

Administration, teaching, training and organisation of study days and workshops. Training multi-disciplinary groups in Sure Start areas. Invited workshops. Study day, 16<sup>th</sup> April, 2003 London.

Sponsored by the Johnson and Johnson Pediatric Institute 2003 and 2004 to make a video on infant behaviour and launch it at a conference in London on March 4<sup>th</sup> and 5<sup>th</sup>, 2004 "Enriching early parent-infant relationships".

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

Brazelton trainer's meeting, Brazelton Institute, Boston, Mass., USA October 22<sup>nd</sup>-25<sup>th</sup>, 2002, Boston, USA : Presented activities of Brazelton Centre in Great Britain, and an intervention study using the NBAS. Developed plans for training trainers. Presentations to be published by Johnson and Johnson Pediatric Institute.

Proposal accepted by Sure Start, Cambridge for Brazelton workshops and training programme, September, 2003.

Steering Committee Member of CAMPIP - Cambridge Parent-Infant Project, an infant mental health project. Organising and speaking at bimonthly meetings.

Management Committee Member of Parents First! - a local charity running sessions for mothers, babies and toddlers.

Member of the Developmental Care Group, NICU, Rosie Hospital. Organised Study Day, November 12<sup>th</sup>, 2002 "Making sense of the senses: Developmental Care in the NICU".

Honorary contract at the Rosie Hospital, Addenbrookes NHS Trust, Cambridge: Providing intervention for parents of babies in the NICU using the NBAS. Two hours per week. Wrote leaflet for parents on infant behaviour.

Sustaining member of the Board of Directors, Chicago Lying-In Hospital, Chicago. Presented paper: "Intervention with the NBAS in the NICU", 10<sup>th</sup> April, 2003.

"Talking head" in Child Development video for teachers and social workers, funded by the Open University and the NSPCC. To be issued 2003.

Research team member of project with the Royal College of Nursing: Information, communication and support for parents of premature babies, 2003.

Parents of preterm babies support group - Consultations with parents and the National Childbirth Trust, who are setting up a group locally, 2002 and 2003.

Teaching modules on parent-infant relationships and infant behaviour and assessment. Homerton College of Health Studies, Cambridge. Ongoing.

## **Claire Hughes**

*Predicting antisocial behaviour and peer problems.*

*Funding body: The Health Foundation (formerly known as the PPP Foundation)*

*Funding period: October 2002-2005*

*Funding value: £215K*

*Co-applicant Professor Judy Dunn, Institute of Psychiatry, London.*

In October 2002 I was awarded a three-year grant from the Health Foundation that provides funding for my PhD student, Rosie Davie, and a research assistant, Rachel Marfleet. The study which we have called "Toddlers Up!" has so far involved recruiting at-risk sample of 140 toddlers (i.e., toddlers from predominantly low income / low education / teen- or single-parent families); visiting them in their homes and having pairs of families come to the CFR to complete mother-child observations and child tests, and to observe the toddlers interacting with a same-sex age-mate. The aims of the study are (i) to identify deviant as opposed to developmentally normative challenging behaviours in toddlers; (ii) to explore the interplay of family and child characteristics that predict the onset and persistence of behavioural problems; and (iii) to identify the nature and influence of peer problems in children at risk of developing disruptive behaviour disorders. Although recruitment has been much more difficult and time-consuming than anticipated (the study is a 'prequel' to a study of 'hard to manage' children that was conducted in a deprived area of London, and for which recruitment was very easy); the study is on target, and data will begin to be available for analysis by the end of this year.

In addition, together with Serena Lecce (a PhD student from the University of Pavia, Italy who completed a research placement at CFR between January and August 2003) I have been



analysing transcripts from my earlier study of 'hard to manage' children, in order to explore contrasts in the quality of the children's interactions with siblings and with friends, and to examine the origins of individual differences in these relationships for hard to manage children and their typically developing peers; this work should be submitted for publication by the end of this year.

Two student volunteers completed research placements working on the Toddlers Up! project: Michelle Byrne, from the University of Chicago, June – September, and Yee San Teoh, from the University of Durham, June – July.

I have also been writing a paper with my PhD student, Rosie Davie, based on a pilot study of toddlers, in which we explore the role of language, verbal ability and emotion understanding in explaining individual differences in prosocial behaviour in toddlerhood.

Earlier this year I submitted a paper to *Child Development*, reporting findings from a study of 'theory of mind' skills in 1100 pairs of five-year-old twins. The results of this study point to the importance of shared environmental influences on individual differences in theory of mind at five years, and so provide an important counterpoint to earlier results indicating strong heritable influence on theory of mind in three-year-olds. This study is based on a study led by my co-authors on this paper, Professors Moffitt and Caspi, at the Institute of Psychiatry in London.

I am currently preparing an application for a five-year MRC Career Establishment Award – this will be ready for submission by March 2004.

#### Other activities

I am employed as a University Teaching Officer for SPS, and as a Fellow of Newnham College. During term time therefore, a substantial proportion of my time is taken up with lecturing, supervision, committee meetings and related administrative duties.

I became an editor of *Infant and Child Development* in January 2003, and of the *British Journal of Developmental Psychology* in March 2003.

This year I have given invited lectures for the East Anglia Child Psychiatry group (held in Cambridge) and for the national society for Paediatric Neuropsychology (held in London).

#### Publications

Booth, R., Charlton, R., Hughes, C. and Happé, F. (2003), "Disentangling weak coherence and executive dysfunction: Planning drawing in Autism and ADHD", *Philos Trans R Soc Lond B Biol Sci*, 358, 387-92.

Hughes, C. (2003), "Making and Breaking Relationships: Children and their Families", in A. Bainham, B. Lindley, M.P.M. Richards and E. Trinder (eds), *Children and Their Families: Contact, rights and welfare*, pp. 33-46, Oxford: Hart.

Brophy, M., Hughes, C. and Taylor, E. (2002), "To Go or Not To Go: Inhibitory control in hard to manage children", *Infant and Child Development*, 11, 125-40.

Hughes, C. (2002a), "Executive functions and development: Emerging themes", *Infant and Child Development*, 11, 201-210.

Hughes, C. (2002b), "Executive functions and development: Why the interest?", *Infant and Child Development*, 11, 69-72.

Hughes, C. and Dunn, J. (2002), "'When I say a naughty word': Children's accounts of anger and sadness in self, mother and friend: Longitudinal findings from ages four to seven", *British Journal of Developmental Psychology*, 20, 515-535.

Hughes, C. and Graham, A. (2002), "Measuring executive functions in childhood: Problems & solutions?", *Child and Adolescent Mental Health*, 7, 131-142.

Hughes, C., Oksanen, H., Taylor, A., Jackson, J., Murray, L., Caspi, A. and Moffitt, T. (2002), " 'I'm gonna beat you!' Gender differences in five-year-olds' response to competitive threat", *Journal of Child Psychology & Psychiatry*, 43, 507-516.

#### In press

Hughes, C. and Leekam, S. (2003), "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*.

Hughes, C., Graham, A. and Grayson, A. (2003), "Executive function in childhood: development and disorder", in J. Oates (ed), *Cognitive Development*, Open University Press.

Hughes, C. (2003), "Origins of individual differences in theory of mind and language: Twin study findings", in J.W. Astington, J. Baird, P. Zelazo and D. Olson (eds), *Why language matters for theory of mind*, New York: Oxford University Press.

Hughes, C. (2003), "Executive function and development", in B. Hopkins (ed), *Cambridge Encyclopedia of Child Development*, Cambridge University Press.

#### **Antonella Invernizzi**

*Children's Exploitation, Socialisation and Participation in Economy. A Comparative Analysis of Child Labour in Peru and Portugal. Grantholder. Funded by the Swiss National Science Foundation. October 2001 - January 2004.*

Nearly one year fieldwork in the Algarve (Portugal) concluded in February 2003. During this fieldwork, I was affiliated as a researcher at the Universidade de Lisboa, Instituto de Ciências Sociais.

I was on maternity leave during the summer (2003).

#### Presentations

"*El trabajo de los niños en el Algarve. Presentación de un proyecto de investigación*". Presentation at the seminar "*Anthropological and sociological research in the Algarve*". University of Algarve, 15<sup>th</sup> November 2002.

"*Working children on the Algarve: family, school and futures*". Presentation at the Centre for Family Research seminar, University of Cambridge, 25<sup>th</sup> February 2003.

#### Publications

Invernizzi, A. (2002), "Des enfants condamnés à travailler ou des enfants acteurs économiques et sociaux ? Éléments de dé-construction des discours sur le travail des enfants", in V. Dasen (ed), *Naître en 2001/Geboren im Jahr 2001: Regards croisés sur la naissance et la petite enfance*, pp. 153-168, Fribourg: Editions de l'Université de Fribourg.

Invernizzi, A. and Milne, B. (2002), "Are children entitled to contribute to international policy making? A critical view of children's participation in the international campaign for the elimination of child labour", *International Journal of Children's Rights*, 10 (4), 403-431.

Invernizzi, A. (2003), "Street-working children and adolescents in Lima: work as an agent of socialization", *Childhood*, 10 (4), 319-341.

Invernizzi, A. and Milne, B. (2003), "The role of the Street for European Children: Examples of problems and resources for children", in I. Colozzi and G. Giovannini (eds), *Young people in Europe. Risk, autonomy and responsibilities*, pp. 35-53, FrancoAngeli. Italian translation: "Il ruolo della strada per i bambini europei: esempi di problemi e risorse", in I. Colozzi and G. Giovannini (eds) *Ragazzi in Europa tra tutela, autonomia e responsabilità*, pp. 42-63, Milano: FrancoAngeli (ISBN: 9 788846 445445)

#### In press

Invernizzi, A. (2003), "Des enfants libérés de l'exploitation ou des enfants travailleurs doublement opprimés? Positions et oppositions sur le travail des enfants", *Déviance et Société*.

### **Dr Julie Jessop**

#### *Senior Research Associate*

From October, 2002 to February, 2003 I was involved in the initial start-up of a three year project looking into anti-social behaviour disorders in young children. (See Dr. Claire Hughes's entry.) The post involved developing recruitment strategies, liaising with schools and health professionals and also interviewing mothers.

I also worked as a Research Consultant on a Joseph Rowntree Foundation project looking at loss, bereavement and young people, based at the Open University.

In October, 2003 I shall be working as part of a three year Wellcome Trust funded bio-ethics project looking at issues surrounding human tissue collection in the UK. The project is based at Kings College, Cambridge and the principal investigator is Dr. Bronwyn Parry.

#### Other activities/interests:

I am a member of Cambridge Socio-Legal Group and have co-written a chapter on fathers after divorce for their latest book on contact. I am also currently writing a chapter on the development of sexuality for publication in their next book to be published in 2004.

I am the co-ordinator of the Qualitative Women's Workshop on Family and Household Research. This is a research group, presently based at South Bank University, which meets bi-monthly to discuss theoretical and analytical advances in feminist research. I have recently completed co-editing a book produced by the Workshop on ethics in qualitative research. I was invited to the University of New York to give a presentation about the book, and also presented a paper at the Fourth International Interdisciplinary Conference of Advances in Qualitative Methods, in Banff, Canada.

#### Recent Publications:

Simpson, R., Jessop, J.A. and McCarthy, P. (2003), "Fathers after divorce", in A. Bainham., B. Lindley, M. Richards and L. Trinder, (eds), *Children and Their Families: Contact, Rights and Welfare*, pp. 201-219, Oxford: Hart.

Hawthorne, J., Jessop, J.A., Pryor, J. and Richards, M. (2003), "Supporting Children Through Family Change: A review of interventions and support services for children of divorcing and separating parents", York: YPS/Joseph Rowntree Foundation.

Mauthner, M., Birch, M., Jessop, J.A. and Miller, T. (eds), (2002), *Ethics in Qualitative Research*, London: Sage Publications.

Duncombe, J. and Jessop, J.A. (2002), "Rapport and the ethics of 'faking friendship'", in M. Mauthner, M. Birch, J.A. Jessop and T. Miller, (eds), *Ethics in Qualitative Research*, London: Sage Publications.

Ribbens-McCarthy, J. and Jessop, J.A. (forthcoming, 2004) "Disrupted Transitions? Bereavement and Young People", Report to the Joseph Rowntree Foundation.

Jessop, J.A. (forthcoming, 2004), "The development of sexuality", in A. Bainham, B. Brooks-Gordon and L. Gelsthorpe (eds), *Sexualities*, Oxford: Hart Publishing.

### **Lynne Jones**

Research activities include completing a book on children's understanding of War in Bosnia (title still to come) to be published next year by Harvard.

Currently working as Mental Health Specialist for International Medical Corps in Iraq.

Invited lecturer to Harvard University Children's initiative symposium on Children and War, April 2003.

Invited lecturer to IACAP symposium 'Children War and Terrorism' in July 2003, Rome.

Continue as tutor in mental health on the international diploma in Humanitarian Assistance course at the Centre for International Health and Cooperation at Fordham University New York

#### Publications

Jones, L. and Kafetsios, K. (2002), "Assessing Adolescent Mental Health in War-Affected Societies: The Significance of Symptoms", *Child Abuse and Neglect: The International Journal*, 26, 1059-1080.

Jones, L. (2002), "Adolescent Understandings of Political Violence and Psychological Well being. A Qualitative Study From Bosnia Hercegovina", *Social Science and Medicine*, 55, 1351-1371.

#### In press

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*.

### **Bridget Lindley**

#### **Research: Qualitative study on advice and advocacy for families in child protection cases**

From 1997-2001, I worked part time at the Centre with Martin Richards on a qualitative study, which explored the process of advocacy for parents in child protection cases, in which the local authority was making enquiries under s.47 Children Act 1989. These enquiries are conducted within an administrative rather than judicial framework. The rationale for the study was that partnership between parents and the local authority is regarded as the fundamental principle underpinning the successful protection of children. Yet it is not always be achievable in every case because where there is a divergence of views between the social worker and the parents about the risk to the child, the social worker's duty to protect the child takes precedence over their role as advocate for the family as a whole, often leaving the parents unsupported. When this occurs, parents may need to be supported by an independent

advocate in order to be able to participate effectively in the process from an informed position. Such advocacy is promoted in government guidance (Working Together, DoH, 1999) but it is not as yet a coherent, nationally run service.

Our research explored the process of advocacy in this context, paying particular attention to the function of advocacy, the professional dilemmas inherent in the advocate's role, and what makes advocacy successful or unsuccessful and was funded by the Nuffield Foundation.

The study found that despite some resistance amongst professionals to the advocate's involvement, there was nevertheless a strong consensus that advocacy is helpful or very helpful provided the advocate has specialist knowledge and experience of the child protection process and issues, conducts him/herself in a professional, non-adversarial manner and becomes involved early on in the process. However, it also showed that there was an urgent need for a national advocacy protocol to be drawn up, giving guidance about professional, ethical and practice issues.

### **Protocol for practitioners:**

In order to address this latter need the Department of Health commissioned Martin Richards and myself to develop a protocol on advice and advocacy for parents in such cases. The protocol draws upon the research evidence, and was also developed in consultation with a wide range of childcare and advocacy organisations, the Department of Health, the ADSS, the Law Society, and members of the judiciary. Broadly, it outlines the practice issues which need to be addressed by both advocates, social workers and other child care professionals when advocates become involved, and also explored the ethical considerations for advocates working in this context, in which the avoidance of collusion with both the parent and the local authority is crucial. It is the first time such a protocol has been developed at a national level. This document is available on [www.doh.gov.uk/acpc/](http://www.doh.gov.uk/acpc/), [www.doh.gov.uk/qualityprotects/](http://www.doh.gov.uk/qualityprotects/), and [www.sps.cam.ac.uk/CFR/advocacyprotocol](http://www.sps.cam.ac.uk/CFR/advocacyprotocol).

### Publications

In addition to the academic papers published early in the project, we also published an article for social work and child care practitioners to ensure wide dissemination amongst practitioners.

Lindley, B. (2003), "Spare a thought for the parents", *Community Care*, August, p 34-35.

### Socio-Legal Group

I am vice chair of the Social-Legal Group, and have been an editor of our recent publication: Bainham, A., Lindley, B., Richards, M.P.M. and Trinder, L. (eds) (2003), *Children and their Families: Contact, Rights and Welfare*, Oxford, Hart. In addition to editing the book with my colleagues, introducing Bob Geldof as a contributor and co-ordinating the project, I also organised the launch party for the book which was held at the Nuffield Foundation on 11<sup>th</sup> September 2003. This event was very successful and was attended by senior members of the legislature and Parliament, and also had some press coverage (see page 2).

### **Rachel Marfleet**

#### *Research Assistant*

I am working with Dr Claire Hughes and Rosie Davie on a research project looking into the early origins of antisocial behaviour in 140 toddlers. I participate in recruitment, home visits, lab visits and other background tasks.

**Shobita Parthasarathy***Wellcome Post-doctoral Fellow***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 political cultures influence 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; and the role and influence of the biotechnology industry. More broadly, I do work in the fields of science & technology studies, medical sociology, political sociology, and bioethics.

*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. (Summer 2003-2006)*

**Short description of project**

My current project uses the European politics over patenting human biotechnology as a case study to investigate the dynamics of globalization in the field of genomic medicine. Scholars and popular writers alike argue that the world is increasingly interdependent, with transnational advocacy groups, multinational corporations, and international laws operating across national boundaries. Attempts to configure European intellectual property law in the area of biotechnology to resemble its American counterpart, however, have not been simple or straightforward. While biotechnology companies and industry lobby associations argue that a strong European intellectual property regime will facilitate transnational research and development and international technology transfer, many European governments and advocacy groups respond that participation in a global patenting regime conflicts with deeply held national identities, interests in promoting innovation for the public good, and commitments to equal access to health care. In these debates, alliances have formed not only within countries, but also transnationally among groups with similar ideological commitments. How do the processes of globalization work? How are national regulatory frameworks, laws, norms, and values reconciled in the international arena, and what roles do transnational advocacy groups play? How do these politics influence the development and governance of science and technology, and what are the implications for the users of genomic medicine? What are the implications of these international politics for national approaches to public health? By investigating how these politics unfold and are resolved, this systematic and empirically in-depth analysis explores the challenges of globalization, its influence on the development of science and technology, and the consequences it has for the global citizen.

**Other activities, lectures or presentations given**

2003 Graduate Student Paper Award, Health/Health Policy Section, Society for Study of Social Problems.

"Symposium on Race and the New Genomics." University of Illinois—Chicago, November 2003.

"Comparing the Grace Period in US and European Patent Law." Dutch Forum on Biotechnology and Genetics, November 2003.

"The Global Politics of a Global Genome." University of Illinois-Chicago Medical Humanities Lecture Series, January 2003.

“A Global Genome? The Transnational Politics of Patenting Human Biotechnology.” Presentation to the American Sociological Association, Atlanta, GA, August 2003.

“A Test Case: Defining the Genetically At-Risk Individual in the United States and Britain.” Presentation to the American Sociological Association, Atlanta, GA, August 2003.

“Producing Genetic Testing for Breast Cancer and Moral Order in the US and Britain.” Conference on *Technologies/Moralities: The Ethical Grammar of Technological Systems*. Virginia Tech University, March 2003.

“The Transnational Politics of Breast Cancer Genetics.” Presentation at the *Society for the Social Studies of Science Conference*, Milwaukee, WI, November 2002.

“The Comparative Politics and Law of Genetic Testing for Breast Cancer in the US and Britain” Northwestern University Sociology Colloquium, Oct. 2002.

### **Publications**

Book Review: “The Breast Cancer Wars” and “A Darker Ribbon.” *Isis*. (forthcoming, 2004.)

“The Universal Book of Life? Trying to Develop an International Testing System of Genetic Testing for Breast Cancer.” *Shaping Science and Technology Policy: The Next Generation of Research*, edited by David H. Guston and Daniel Sarewitz, University of Wisconsin Press, forthcoming (expected publication, 2004).

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

“Knowledge is Power: Constructing the User of Genetic Testing for Breast Cancer in the US and Britain” in *How Users Matter*. Trevor Pinch, Nelly Oudshoorn, eds. Cambridge, MA: MIT Press (October 2003).

### **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).

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.

#### Publications

Richards, M., Ponder, M., Pharoah, P., Everest, S. and MacKay, J. (2003) "Issues of consent and feedback in a genetic epidemiology study of women with breast cancer", *J Med Ethics*, 29, 93-96.

### **Ilina Singh**

#### Research Activities

Pilot research for a project that involves children with ADHD and their parents to understand the implications of drug treatment for children's sense of self and personal agency.

Research into the history of Ritalin advertising, involving a systematic survey of advertising in medical journals from 1955-1975, and in the popular American media, from 2000 - present.

#### Teaching:

History and Culture of Psychopharmacology (in HPS). Gender and the Family (SPS). Gender and Psychopathology (SPS). Bioethics (Medical School)

#### Editorial Work:

Managing Editor, *BioSociety*

Journal proposal under review by Cambridge University Press; journal launch expected 2004 (Co-Editors, Nikolas Rose, LSE, and Anne Harrington, Harvard)

#### Invited Lectures

"Moral Dilemmas and Ritalin Riddles", Dept. of Psychological Medicine, Hergest Unit, Cardiff. December, 2003.

"Moral Dilemmas and Ritalin Riddles", Vital Politics Conference, LSE, October, 2003.

"Bettering Boys: The Role of Psychopharmacology", Psychology Department Seminar, Lancaster University. March, 2003.

"Bettering Boys: The Role of Psychopharmacology", Social Psychology Departmental Seminar, LSE. December, 2002.

#### Publications

Singh, I. (2002), "Biology in context: social and cultural perspectives on ADHD", *Children and Society*, 16, 360-367.

Singh, I. (2002), "Bad boys, good mothers and the 'miracle' of Ritalin", *Science in Context*, 15(4), 577-603.



In press

Singh, I. (2003), "Doing their jobs: Mothering with Ritalin in a culture of mother-blame", *Social Science and Medicine*.

Singh, I. (2003), "Boys will be boys: Fathers' perspectives on ADHD symptoms, diagnosis and drug treatment", *Harvard Review of Psychiatry*.

**Claire Snowdon*****Research Associate*****Views of participants in neonatal randomized controlled trials**

In recent years three related studies have been carried out, focusing on the views of participants in trials.

The first study was funded by the Department of Health and Wellcome through the National Perinatal Epidemiology Unit and 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 was developed further as a research fellow at the London School of Hygiene and Tropical Medicine, funded by The Nuffield Foundation. It examines the same issues with two neonatal trials (The INNOVO Trial, the CANDIA Trial) and two antenatal trials (the TEAMS Trial and ORACLE). It involves approximately 120 interviews with staff and parents linked to these trials. Analysis of the data is underway. Papers are in preparation on professional and parental attitudes to post mortems for clinical trials (in press), views of parents who refuse trial participation, views of bereaved parents, doctors attitudes to the ethical foundations of trials (equipoise).

Data were collected for a third related study during 2002. The study was funded by Heartlink and collected tapes of informed consent procedures with follow up interviews of parents whose babies were included in a pre-trial study of the safety and feasibility of hypothermia and ECMO. Funds are being sought to analyse and write up these data.

***Investigation into factors and interventions associated with good and poor recruitment to multicentre trials. Funded by MRC and the NHS HTA Programme. March 2002 - February 2004.***

With colleagues at the Health Services Research Unit, University of Aberdeen, and the London School of Hygiene and Tropical Medicine, the study examines factors affecting recruitment to trials from three perspectives. The study involves an epidemiological review of trial data, a qualitative interview study involving trial principal and local investigators, trial managers and local recruiters.

Publications

Elbourne, D.R., Snowdon, C. and Garcia, J. (forthcoming 2003), "Perinatal postmortem examinations: views of clinicians and bereaved parents", 12 September 2003, online journals, <http://bmj.bmjournals.com>

Green, J.M., Kafetsios, K., Statham, H.E. and Snowdon, C.M. (2003 in press), "Factor structure, validity and reliability of the Cambridge Worry Scale in a pregnant population", *Journal of Health Psychology* 8(6).

Snowdon, C., Garcia, J. and Elbourne, D. (2002), "Decisions, Decisions: How Do Parents View the Decision They Made About a Randomized Clinical Trial?", in K. W. M. Fullford, D. L. Dickenson and T. Murray (eds), *Healthcare Ethics and Human Values: An Introductory Text with Readings and Case Studies*, pp. 261-269, Blackwell.

In press

Snowdon, C., Elbourne, D., Garcia, J. (2003), "Perinatal pathology in the context of a clinical trial: a review of the literature", *Archives of Diseases in Childhood*.

Snowdon, C., Elbourne, D., Garcia, J. (2003), "Perinatal pathology in the context of a clinical trial: attitudes of neonatologists and pathologists", *Archives of Diseases in Childhood*.

Snowdon, C., Elbourne, D., Garcia, J. (2003), "Perinatal pathology in the context of a clinical trial: attitudes of bereaved parents", *Archives of Diseases in Childhood*.

Snowdon, C., Elbourne, D., Garcia, J. (2003), "Perinatal pathology in the context of a clinical trial: summary of attitudes of bereaved parents", *Archives of Diseases in Childhood*.

**Dr Bryn Williams-Jones**

*Post-doctoral Fellowship, Research Council of Canada*

Research Projects

My first year in Cambridge was devoted to publishing articles from my PhD thesis, initiating contacts with researchers working in the area of university-industry relations, and developing an understanding of the University of Cambridge genetics and genomics communities and their interaction with industry. With Oonagh Corrigan, I have begun exploring the social and ethical issues in pharmaceutical research, pharmacogenomics, and clinical research trials. We are also seeking funding for a three year research project entitled *Charting the Genesis and Expansion of Ethical, Legal, and Social Issues (ELSI) Programmes Involved in the Governance of Human Genetics and Genomics in the UK*. This project aims to provide a detailed analytic account of the historical emergence and development of ELSI research programmes in the UK, and is part of a larger comparative project between Canada and the UK. The UK arm will be submitted to the Wellcome Trust in December, while a parallel grant proposal for the Canadian arm will be submitted to the Social Sciences and Humanities Research Council of Canada in October.

Publications

Corrigan, O.P. and Williams-Jones, B. (2003), "Consent is not enough...putting incompetent patients first in clinical trials" [Commentary], *The Lancet*, 361(9375), 2096-2097.

Williams-Jones, B. (2003), "Where there's a web, there's a way: Commercial genetic testing and the Internet", *Community Genetics*, 6(1), 46-57.

Williams-Jones, B. (2002), "History of a gene patent: Tracing the development, marketing, and application of commercial BRCA testing in Canada", *Health Law Journal*, 10, 121-144.

Williams-Jones, B. (2002), "Can bioethics save biotechnology?" Review of Rahul K. Dhanda's *Guiding Icarus: Merging Bioethics with Corporate Interests*, *Canadian Medical Association Journal*, 167(4), 381-382.

In press

Williams-Jones, B. and Burgess, M.M. (2003), "Social contract theory and just decision-making: Lessons from genetic testing for the BRCA mutations", *Kennedy Institute of Ethics Journal*.

Williams-Jones, B. and Corrigan, O.P. (2003), "Rhetoric and hype: Where's the 'ethics' in pharmacogenomics?", *American Journal of Pharmacogenomics*.

Williams-Jones, B. and Graham, J. (2003), "Actor-network theory: A tool to support ethical analysis of commercial genetic testing", *New Genetics and Society*.

Williams-Jones, B. (2003), "University-industry relations and some lessons from biotech", *Canadian Chemical News/L'Actualité chimique canadienne (ACCN)*, April, Issue 7, 20-21. (<http://chem4823.usask.ca/~cassidy/Bryn-UniversityIndustry.htm>)

Presentations

*Surrogacy, Cloning, and Designer Babies: Ethics and Infertility Technologies*, Master of Studies in Primary and Community Care, Homerton School of Health Studies, Cambridge, June 18, 2003.

*The Clinic & the Workplace: Implications of Commercial Genetic Testing*, Cambridge Genetics Knowledge Park seminar, University of Cambridge, May 9, 2003.

*Of Patents & Democracy: Commentary on Morgan's "After the Glass Bead Game: Living with the Troubled Helix"* (Invited Presentation) Roundtable Discussion on Bioethical Issues of IPRs, Law Faculty, University of Cambridge, Mar. 29, 2003.

*Social and Ethical Issues in Biotechnology*, Year 2: Biological Sciences (Bioethics), Faculty of Education and Homerton College, University of Cambridge, Feb. 18, 2003.

*History of a Gene Patent: Tracing the Development, Marketing, and Application of Commercial BRCA Testing*, ESRC Centre for Genomics in Society, Seminar Series, University of Exeter, Feb. 11, 2003. Re-presented at the Sheffield Institute of Biotechnological, Law and Ethics, University of Sheffield, Feb. 26, 2003.

*Where There's a Web, There's a Way: Commercial Genetic Testing and the Internet*, Genetic Testing: Help, Hope or Hype?, Centre for Health Services and Policy Research, University of British Columbia, Vancouver, B.C., Nov. 8, 2002. Re-presented at the Genetics Group, Centre for Family Research, University of Cambridge, Oct. 14, 2002, and at the Genetics and Law Conference, London, Nov. 19, 2002.

TeachingSupervision/Tutorial

Discussant, Year 2: Biological Sciences (Bioethics), Faculty of Education and Homerton College, University of Cambridge, Feb.-Mar. 2003.

Supervisions with students.

Professional Activities

2003-: Member, Board of Trustees (& Finance and General Purposes Committee), Homerton College, Cambridge.

Jan. 2003: Participant in the Democracy, Ethics and Genomics workshop, Centre for Applied Ethics, University of British Columbia.

2002-: External member, Standing Committee on Fellowships and Career Development, Social Sciences and Humanities Research Council of Canada, Ottawa.

### **Dr Anji Wilson**

#### *Research Associate*

*Understanding Inheritance: Kinship Connections and Genetics (with Martin Richards). Funded by The Wellcome Trust 2000-2003*

#### Current Research

I have been working on a qualitative study investigating concepts of inheritance, genetics, family and kinship in a non-clinical sample of students and parents of young children. The study has involved over sixty pilot and full study interviews, which have been transcribed and are being analysed. Papers on lay concepts of inheritance and family obligations are currently in preparation. Further funding to study these concepts in samples from different ethnic backgrounds and younger individuals will be sought.

#### Other Activities

September 2002: presented poster at BSA Medical Sociology Group, 34<sup>th</sup> Annual Conference, University of York

April 2003: introduced current research work at joint Cardiff-Cambridge Social Science and Genetics meeting, Gregynog, Powys, University of Wales

May 2003: attended trans-disciplinary conference, Who Twists the Helix, University of Cambridge

All year: co-ordinated Centre for Family Research Tuesday lunchtime seminar series

#### Publications

Wilson, A., Edwards, J., Allen, S. and Dasgupta, C. (2003), "Schools and Family Change: School-based support for children experiencing divorce and separation", (Family Change Series). York: YPS/Joseph Rowntree Foundation.

Cooper, P.J., Murray, L., Wilson, A. and Romaniuk, H. (2003), "Controlled trial of the short- and long-term effect of psychological treatment of post-partum depression: 1. Impact on maternal mood", *British Journal of Psychiatry*, 182, 412-419.

Murray, L., Cooper, P.J., Wilson, A. and Romaniuk, H. (2003), "Controlled trial of the short- and long-term effect of psychological treatment of post-partum depression: 2. Impact on the mother-child relationship", *British Journal of Psychiatry*, 182, 420-427.

## ASSOCIATE MEMBERS

### Dr Andrew Bainham

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

I have continued to contribute to the reform of the child protection and adoption laws in Romania. I have addressed parliamentarians, lawyers, social workers and the mass media in Bucharest and contributed to the public awareness campaign of the European Union's Delegation in Romania. In the UK, I have served as an Associate of the National Family and Parenting Institute. I have continued as Chair of the Cambridge Socio-Legal Group and as editor of the International Survey of Family Law.

#### Publications

Bainham, A., Lindley, B., Richards, M. and Trinder, L. (eds) (2003), *Children and Their Families : Contact, Rights and Welfare*, Oxford: Hart.

Bainham, A. (2003), "Contact as a right and obligation", in A. Bainham, B. Lindley, M. Richards and L. Trinder (eds), *Children and Their Families: Contact, Rights and Welfare*, pp. 61-88, Oxford: Hart.

Bainham, A. (ed) (2003), *The International Survey of Family Law*, Bristol: Jordans.

Bainham, A. (2003), "Men and women behaving badly: Is fault dead in English family law?", in S. Parker and J. Dewar (eds), *Family Law : Processes, Practices and Pressures*, Oxford: Hart.

Bainham, A. (2003), "International adoption from Romania : Why the moratorium should not be ended", *Child and Family Law Quarterly* 15, 223-236.

### Shelley Day Sclater

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

Dr Shelley Day Sclater works part time at the Centre for Narrative Research, University of East London, and part time as a freelance writer and researcher. Shelley was co-founder, with Martin Richards and Andrew Bainham, of the Cambridge Socio-Legal Group.

Her research interests broadly include:

- qualitative and narrative methodologies
- psychological and socio-legal studies of families, parents and relationships
- applications of psychoanalysis in social research
- theoretical work on subjectivities

She is currently working on 2 books: The first is a 'popular' book on Sexual Attraction. The other involves working with students from a range of cultural backgrounds to produce personal narratives of their diverse experiences of 'family'.

Recent publications include a co-edited interdisciplinary book on surrogacy, a co-edited special issue of the journal *Qualitative Inquiry* on 'Narrative and Art', several book chapters and refereed papers, as well as articles in popular magazines.

Bainham, A., Day Sclater, S. and Richards, M. (eds) (2002). *Body Lore and Laws*, Oxford, Hart.

- Cook, R., Day Sclater, S. and Kaganas, F. (eds) (2003), *Surrogacy: International Perspectives*, Oxford, Hart.
- Sarnnivaara, M. and Bochner, A. (eds) (2003), *Arts and Narrative Inquiries, Special Issue of the Journal Qualitative Inquiry* 9 (4) (S Day Sclater, Deputy Editor).
- Day Sclater, S. (2003), "Epilogue: Art as Inquiry", in M. Saarnivaara and A. Bochner (eds), *Arts and Narrative Inquiries, special issue of Qualitative Research* 9(4):621-624.
- Day Sclater, S. (2002), "Introduction", in A. Bainham, S. Day Sclater and M. Richards (eds), *Body Lore and Laws*, Oxford, Hart.
- Cook, R., Day Sclater, S. and Kaganas, F. (2003), "Introduction", in R. Cook, S. Day Sclater and F. Kaganas (eds), *Surrogacy: International Perspectives*, Oxford, Hart.
- Day Sclater, S. and Kaganas, F. (2003), "Contact and mothers' rights", in A. Bainham, B. Lindley, M. Richards and L. Trinder (eds), *Parents and Children: Contact, Rights and Welfare*, Oxford, Hart.
- Day Sclater, S. (2003), "What is the subject?", in C. Squire (ed), *Questions of Narrative; special issue of Narrative Inquiry* (in press).
- Kaganas, F. and Day Sclater, S. (forthcoming) "Contact Disputes: Narrative Constructions of Good Parents", *Feminist Legal Studies*.
- Andrews, M., Day Sclater, S., Squire, C. and Tamboukou, M. (2003), "Stories of Narrative Research", in C. Seale, D. Silverman, J. Gubrium and G. Gobo (eds), *Qualitative Research Practice*, London, Sage (in press).

### **Dr Gail Ewing**

#### Research interests:

Provision of primary care services; health visiting, palliative care. Qualitative methodologies; grounded theory. Early motherhood, infant feeding and weaning.

#### Research projects:

*Symptoms and needs assessment in the provision of palliative care in the community. A comparison between patients, carers and their primary health care teams. Grant holders: C J Todd, G Ewing, SIG Barclay and J McCabe. Formerly Health Services Research Group Institute of Public Health, Cambridge. Funded by Dept of Health, Community Services Initiative, 1998-2002.*

*Early Motherhood and Infant Weaning: Lay and professional accounts of the weaning process. Grant holder and Project Director: Dr J.M. Green, Mother and Infant Research Unit, University of Leeds. Funded by Anglia and Oxford NHS Executive. 1996-2002.*

#### Publications in press

Ewing, G., Todd, C., Rogers, M., Barclay, S., McCabe, J. and Martin, A. (2003), "Validation of a symptom measure suitable for use amongst palliative care patients in the community: CAMPAS-R", *Journal of Pain and Symptom Management*.

**Dr Nina Hallowell**

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

Interests and activities:

Whilst my main research interest lies in the social and ethical implications of the new genetic technologies, my research also focuses upon the sociology of risk, research ethics, lay understandings of disease and medical interventions and lay-professional interaction.

Current Research Projects

*'South Asian Patients' experiences of Scottish Diabetes Services: A qualitative study. Chief Scientist Office. £45,526. October 2003-2004 ( J. Lawton, N. Hallowell, L.Hanna, & M. Douglas)*

*'Psychosocial effects of molecular genetic diagnosis: the case of X-linked learning disability.' Wellcome Trust, £130,000, October 2002-2006 (M.P.M. Richards, N.Hallowell & L. Raymond).*

*The implications of BRCA1 and BRCA2 mutation testing for high-risk men and their families'. Cancer Research UK, £120,000, Feb. 2002- June 2004 (M. Watson, C. Foster, C. Moynihan & N.Hallowell)*

Publications

Hallowell, N., Foster, C., Eeles, R., Ardern-Jones, A., Murday, V. and Watson, M. (2003), "Balancing autonomy and responsibility: the ethics of generating and disclosing genetic information", *Journal of Medical Ethics*, 29, 74-79.

Hallowell, N. (2003), "A response to Angus Clarke "Family obligations and the limits to 'autonomy'"", *Journal of Medical Ethics*, 29, 79.

Hallowell, N. (2003), "Ethics and evidence", in D.N. Cooper (ed), *The Encyclopedia of the Human Genome*, London, Nature Publishing Group.

Hallowell, N., Foster, C., Eeles, R., Ardern-Jones, A., Murday, V. and Watson, M. (2002), "Genetic testing for women previously diagnosed with breast/ovarian cancer: examining the impact of BRCA1 and BRCA2 mutation searching", *Genetic Testing*, 6(2), 79-87.

Hallowell, N. and Lawton, J. (2002), "Negotiating present and future selves: decision-making about prophylactic surgery for hereditary ovarian cancer", *Health* 6(4), 423-443.

Hallowell, N., Mackay, J., Richards, M.P.M., Gore, M. and Jacobs, I. (in press), "High-risk premenopausal women's experiences of undergoing prophylactic oophorectomy: a descriptive study", *Genetic Testing*.

**Professor Juliet Mitchell**

*Faculty of Social and Political Sciences and Fellow of Jesus College*

Research interests

My research has concentrated on producing a book "Siblings: Sex and Violence" to be published by Polity Press, October 2003.

### Publications

- Mitchell, J. (2002), "Natasha and Hélène in Tolstoy's *War and Peace*: gender conventions and creativity", in F. Moretti (ed), *le Romano* vol. III, Rome: Editore Einaudi.
- Mitchell, J. (2002), "la reconnaissance du traumatisme et la place du langage", *Report of the Paris Psychoanalytic Society*, (in press)
- Mitchell, J. (2002), "On First Looking into Freud's Lecture on Femininity", Review Feature in *European Journal of Psychotherapy Counselling and Health*, London: Taylor, Francis and Routledge. *Psychoanalysis and Psychotherapy: Women in Psychoanalysis: Memos for Future Historians*.
- Mitchell, J. (2002), "Psychoanalysis and Feminism at the Millennium", in E. Bronfen, and M. Kavna (ed), *Feminist Consequences: Theory for a New Century*, Columbia University Press.
- Mitchell, J. (2002), "Psychoanalysis, Sexuality and Social Changes", in A. Molino and C. Ware (eds) *Where Id was*, London: Routledge.
- Mitchell, J. (2002), (with Sigal Spigel), "The Power of Abstraction" in Review of Nancy Chodorow's *The Power of Feelings*, in *Psychodynamic Practice*, London.
- Mitchell, J. (2002), "Sexuality in the Twenty-first Century", *Tropicos, Journal of the Caracas Psychoanalytical Society*, vol. 2, Pages 80-84, November 2002.
- Mitchell, J. (2002), "Psykoanalys och feminism vid tusenårsskiftet", *Divan. Tidskrift för psykoanalys och kultur*, 1-2/2002, pp.101-110.
- Mitchell, J. (2002), "What Is The Difference Between Gender And Sexual Difference?", *Psykotera. ISSN 0350-601x*.
- Mitchell, J. (2002), Response to: Lynne Segal: "Psychoanalysis and Politics: Juliet Mitchell, Then and Now", *Studies in Gender and Sexuality*, 3(2), 217-228.

### **Dr Deborah Thom**

*College lecturer, Director of Studies in History and tutor Robinson College Cambridge*

Taught on papers on bio-engineering and the family in SPS IIB; on the history of British psychology in HPS and on a new course for the History Tripos part 1 Themes and Sources on The Body in History as well as on the history of the politics of gender in part II.

### Publications

- Thom, D. (2002), "Gender and history: la premiere du genre", *Clio*, 16.
- Thom, D. (2003), "Citizen of empire or juvenile delinquent", in M.Gwirjke-Hofstra and H. Msarland (eds), *Cultures of Child Health in Britain and the Netherlands in the Twentieth Century*, Rodopi.
- Thom, D. (2003), "Making war spectacular", in G. Braybon, (ed), *Evidence, History and the Great War: a re-assessment*, Berghahn, in press.



## VISITORS

### 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 spent 6 months at the Centre as a visiting researcher, working with Dr Claire Hughes on a project on "hard to manage" children's relationships with their friend and sibling. The main goal of the study was to investigate how "at risk" children use their cognitive and emotional abilities in real life. This year she hopes to write a paper with Dr Claire Hughes outlining differences in children's talk about inner states in their conversations with siblings and friends.

### Ann Robertson

*Associate Professor, Department of Public Health Sciences, University of Toronto  
Visiting Scholar, Centre for Family Research, October 2002 – June 2003*

#### Research

2002- 2003, Canadian Institutes of Health Research (Institute of Genetics) Career Transition Award - to study policy issues at the intersection of human genetics, bioethics and public health, under the mentorship of Dr. Martin Richards.

#### Grants held

2003-2005, Principal Investigator, "It's all in our genes": A Critical Analysis of Media Representations of Genetic Risk for Breast Cancer". Funded by Social Sciences and Humanities Research Council (SSHRC) of Canada, \$48,500.

2000-2005, Co-Investigator, "International and Comparative Perspectives on the Regulation of Genomic Research and Health Systems and Insurance" (Dr. Trudo Lemmons, PI). Project of Canadian Program on Genomics and Global Health (Dr. Peter Singer, Director) Funded by Genome Canada/Genome Ontario. \$1,000,000.

2000-03, Principal Investigator, "Towards a Phenomenology of Risk: The Case of Genetic Testing for Breast Cancer." Funded by Social Sciences and Humanities Research Council (SSHRC) of Canada. \$40,000.

#### Publications

Denny, K., Coburn, D., Mykhalovskiy, E., McDonough, P., Robertson, A. and Love, R. (2003), "Population Health: A Brief Critique", *American Journal of Public Health*, 93 (3), 392-396.

Buckeridge, D., Mason, R., Robertson, A., Frank, L., Glazier, R. and Purdon, L. with C. G. Amrhein, N. Chaudhuri, E. Fuller-Thompson, P. Gozdyra, D. Hulchanski, G. Moldofsky, M. Thompson and Wright, R. (2002), "Health Data Maps: A Case Study of a Community/ University Research Collaboration", *Social Science and Medicine*, 55 (7), 1189-1206.

## INTEREST GROUPS AND WORKSHOPS

### Cambridge Genetics Group

This group brings together researchers and graduate students interested in the social, psychological, ethic and legal aspects of the new human genetics from across the University and health services. The Group has met fortnightly in term with papers being presented by members usually concerned with work in progress and also from visitors from elsewhere. A particularly notable seminar was that given by Professor Dorothy Wertz from Harvard in March. Very sadly this proved to be her last seminar in Britain and the group were shocked to hear of her death on 29<sup>th</sup> April at Cancun in Mexico. She suffered a heart attack while scuba diving which had been a lifelong passion. Dorothy was a pioneer of studies of genetic clinical practice and attitudes and her flamboyant presence and challenging contributions at seminars and conferences will be much missed.

In April the group held a 2-day residential joint seminar at the University of Wales' conference centre at Gregynog with colleagues from Cardiff. This continues a series of stimulating collaborative meetings that have been held on a more or less annual basis.

Organisers for the Group for 2003/4 are Dr Oonagh Corrigan (email: [opc22@cam.ac.uk](mailto:opc22@cam.ac.uk)) and Dr Bryn Williams-Jones (email: [bw244@cam.ac.uk](mailto:bw244@cam.ac.uk)) who will be pleased to hear of anyone who wishes to join the group's email circulation list.

Martin Richards

### Cambridge Body Research Group

The Body Research Group is currently inactive but we are hoping to have a new series of seminars running again in the near future.

The group, which emerged from an informal programme of seminars on the body in the Faculty of Social and Political Sciences from 1999, exists to promote research and teaching on the body in contemporary society and culture. It is an interdisciplinary group that has drawn heavily from recent interest in the sociology and anthropology of the body, but it welcomes participants from related disciplines in the arts, humanities, and social sciences. The principal focus of research interest in the early development of the programme was in the sociology of health and illness, and research contributions to the seminar series ranged for example over representations of ageing, anorexia, sexual interaction, reproductive technologies, addiction, the work of Michel Foucault, thalidomide victims, and social theories of embodiment.

The Body Research Group is connected through Bryan Turner to the journal *Body & Society*, published by Sage (London). Elizabeth Chapman (former Secretary to the Group) is a member of the editorial board of the newly formed Elsevier Journal - *Body Image: An International Journal of Research*. Another key/founder member of the Body Research Group is Darin Weinberg whose primary interests include medical sociology, urban sociology, the sociology of science, social theory, and deviance.

Further details of many of the past seminars can be found on the web site:

<http://www.sps.cam.ac.uk/body/Activities.html>

Liz Chapman

## Brazelton Centre

Please see under Dr Joanna Hawthorne's entry.

## Cambridge Socio-legal Group

### The history of the group

The Cambridge Socio-Legal Group was formed in 1997 when Professor Martin Richards of the Centre for Family Research, Faculty of Social and Political Sciences, met with Dr. Andrew Bainham to discuss ways in which lawyers and social scientists in Cambridge, with a common interest in the family, might work more closely on subjects of mutual interest. They were quickly joined by Dr. Shelley Day Sclater, formerly of the Centre for Family Research and now Reader in Psychosocial Studies at the University of East London. Together these three were the founder members of the Group.

In 1998 it held a series of seminars on the subject of Law and Parenthood resulting in the book, *What is a Parent? : A Socio-Legal Analysis*, published by Hart publishing of Oxford in 1999. The Group's second project was concerned with Law and the Human Body. This followed the same pattern of a series of seminar days and the publication of the book, *Body Lore and Laws*, again by Hart, in 2002.

The Group adopted a constitution in January 2002 and is now both an Interest Group within the Centre for Family Research and an Associated Research Group of the Faculty of Law. Elections were held at the end of 2002. Andrew Bainham of the Faculty of Law was elected Chair, with Bridget Lindley of the Centre for Family Research as Vice-Chair. The Management Committee consists of the Chair and Vice-Chair (ex officio), Belinda Brooks-Gordon, Loraine Gelsthorpe, Martin Richards and Liz Trinder. Martin Johnson of the Department of Anatomy initially served on the Management Committee and remains actively involved with the Group and its projects.

In 2002 the Group held seminars on the subject of contact between children and members of their family in its many different manifestations. A book entitled *Children and Their Families: Contact, Rights and Welfare* was published, in what has become a series, by Hart in September 2003. A very successful launch event for the book was hosted by The Nuffield Foundation and organised by Bridget Lindley. Three of the editors and one the contributors (Bob Geldof) spoke at the launch which was attended by many professionals in the field and those from voluntary organisations. We were delighted to welcome Cherie Booth among our guests. The event and book achieved a good deal of media coverage (see p.2).

A fourth project on Sexuality was the topic of a 3-day residential seminar held on March 31 - April 2 at Pembroke College. The chapters from this were very successful and lively seminars are now being edited for the next volume in our series. Two further seminars/books, on death and kin care are in the early planning stages.

Throughout its existence the Group has drawn together scholars from within and outside Cambridge and from a wide variety of disciplines. Further details of those who have contributed to the Group's publications are set out below. It is worth mentioning in particular that the Group has informal links with the Oxford Centre for Family Law and Policy. The Group's second book, *Body Lore and Laws*, was launched at the Oxford Centre following a joint seminar day at which papers were presented by members of the CSLG and OXFLAP. Several members of OXFLAP (Ann Buchanan, John Eekelaar, Jonathan Herring, Joan Hunt and Mavis Maclean) contributed to the Group's project on Contact and the *Children and*

*Their Families* book. The Group also has close ties with the School of Social Work and Psychosocial Studies at the University of East Anglia some of whose members contributed to the project on Contact.

#### The group's projects and publications

##### **What is a Parent? : A Socio-Legal Analysis**

The Group's first book was edited by Andrew Bainham, Shelley Day Sclater and Martin Richards and published by Hart in 1999. Those who contributed chapters (in chapter order) were Andrew Bainham; Martin Johnson; Stuart Bridge; Jonathan Herring; Juliet Mitchell and Jack Goody; Rachel Cook; Ros Pickford; Susan Golombok; Allison James; Bridget Lindley; Loraine Gelsthorpe; Wendy Solomou, Margaret Ely, Carol Brayne and Felicia Huppert; Mavis Maclean and Martin Richards; Shelley Day Sclater and Candida Yates.

Julie Jessop and Frances Murton, both of the Centre for Family Research, acted as Discussants in the seminars, preparing the index and acting as sub-editor respectively. In all three of its projects to date, the Group has received invaluable secretarial and technical support from Jill Brown and Sally Roberts also of the CFR.

##### **Body Lore and Laws**

The Group's second book was published in January 2002 and was again edited by Andrew Bainham, Shelley Day Sclater and Martin Richards and published by Hart. Chapters were contributed by (in chapter order) Shelley Day Sclater; Eileen Richardson and Bryan Turner; Jonathan Herring; Gregory Radick, Mavis Maclean, Martin Johnson; Felicity Kaganas; Anne Bottomley; Richard Collier; Andrew Bainham; Belinda Brooks-Gordon and Loraine Gelsthorpe; Rachel Cook; Jane Weaver; John Keown; Caroline Bridge; Martin Richards; Elizabeth Chapman and Derek Morgan. On this occasion the Group was fortunate to have the assistance of Julie Jessop as sub-editor.

##### **Children and Their Families : Contact, Rights and Welfare**

The seminars for the Group's third project were completed in 2002 and the resulting book was published by Hart in September 2003. The book was edited by Andrew Bainham, Bridget Lindley, Martin Richards and Liz Trinder. Those who have contributed chapters (in chapter order) are Liz Trinder; Judy Dunn; Claire Hughes; Jan Pryor; Andrew Bainham; Jonathan Herring; Mavis Maclean and Katrin Mueller; Adrian James; Shelley Day Sclater and Felicity Kaganas; Bob Geldof; Bob Simpson, Julie Jessop and Peter McCarthy; Jo Miles and Bridget Lindley; John Eekelaar; Elsbeth Neil; Martin Richards; Belinda Brooks-Gordon; Donna Smith; Ann Buchanan and Joan Hunt. Frances Murton acted as sub-editor.

All three books are available from bookshops or direct from Hart Publishing Ltd ([www.hartpub.co.uk](http://www.hartpub.co.uk))

##### **Project on Sexuality**

This project is being organised by an editorial team consisting of Belinda Brooks-Gordon, Loraine Gelsthorpe, Martin Johnson and Andrew Bainham. Those who presented papers and are writing chapters include (in the order of the programme) Martin Johnson, Lynne Segal, Michael Freeman, Joanna Phoenix, Roger Ingham, Andrew Bainham and Belinda Brooks-Gordon, Zoe-Jane Playdon, Jonathan Herring and Pak-Lee Chau, Andrew Webber, Jeffrey Weeks, Craig Lind, Linda McDowell, Kerry Petersen, David Pearl, Ken Plummer, Anne Bottomley, Julie Jessop, Emma Longstaff, Marc Desautels and Tracey Kenworthy. The book will be published in 2004.

The finances of the group

The Group is self-financing and such expenses as it has are met from the royalties which it receives from its publications.

Andrew Bainham, Martin Richards

**LUNCHTIME SEMINARS 2002/2003**

held at the Centre for Family Research

**Michaelmas 2002**

15<sup>th</sup> October. Trudy Stevens (Doctoral student, practising midwife) *I'd rather be knackered than demented! An ethnographic study of a 'Changing Childbirth' model of maternity care.*

29<sup>th</sup> October. Anna Bagnoli (Centre for Family Research) *Between an outcast and an outsider: constructing the identity of the foreigner.*

26<sup>th</sup> November. Helen Statham (Centre for Family Research) *Late termination of pregnancy and feticide: law, policy and the impact on parents and health professionals.*

3<sup>rd</sup> December. Karen Henwood (School of Medicine, Health Policy and Practice, University of East Anglia) *Masculinities, identities and the transition to fatherhood.*

**Lent 2003**

28<sup>th</sup> January. Silvana Santos (Visiting Scholar from São Paulo, Brazil) *Genesis and diversity of the explanations about inheritance.*

11<sup>th</sup> February. Martin Richards (Centre for Family Research) *Complex marriage and stirpiculture in the Oneida Community 1848-1880 (an illustrated talk).*

25<sup>th</sup> February. Antonella Invernizzi (Centre for Family Research) *Working children on the Algarve: family, school and futures.*

11<sup>th</sup> March. Jo Green (The mother and Infant Research Unit, University of Leeds) *Greater expectations? Changes in women's expectations and experiences of intrapartum care from 1987 to 2000.*

**Easter 2003**

20<sup>th</sup> May. Claire Snowdon (Centre for Family Research) *Views of participants in clinical trials.*

22<sup>nd</sup> May. Aimee Yates (Addenbrookes Hospital, Cambridge) *Using music therapy to facilitate the mother-baby relationship.*

3<sup>rd</sup> June. Charlotte Wilson (Brookside Family Consultation Clinic, Cambridge) *Exploring the thoughts and behaviours of parents of hard to manage children.*

10<sup>th</sup> June. Elvidina Adamson-Macedo (University of Wolverhampton) *Health psychology and the hospitalised pre-term neonate: assessment, interventions and new paradigms.*

24<sup>th</sup> June. Serena Lecce (Department of Psychology, University of Pavia) *(In)congruence in siblings' and friends' dyads: another possible variable in studying children's relationships.*

**The Margaret Lowenfeld Library**

The library of the Institute of Child Psychology is housed in our premises. This came to us through the Lowenfeld Trustees. The book collection is in the process of being added to the main University Library Newton catalogue. We also have been given some archival material relating to Dr Lowenfeld and the Institute of Child Psychology, and recent additions include research papers from the late Terence Moore, and the Lydia Jackson correspondence from the Leeds Russian Archive. The library also includes books given by Professor Harry Highkin following the death of his wife Elspeth, who was a research student in the Centre at the time of her death.