UNIVERSITY OF
NEWCASTLE UPON TYNE

PAEDIATRIC and LIFECOURSE
EPIDEMIOLOGY RESEARCH GROUP

## School of Clinical Medical Sciences

# Paediatric and Lifecourse Epidemiology Research Group

# Report

# 2002-2004

# Contents

# Foreword

I am delighted to present this first report from the **Paediatric and Lifecourse Epidemiology Research Group**. It is a little over two years since we formed, and I believe that we have made considerable progress since then, in what can only be described as a challenging research environment. We have published over 150 original papers and several individual members have been awarded prizes. Our findings have been presented at national and international conferences all over the world and reported extensively in local and national newspapers, on the radio and on TV.

Research, especially in epidemiology is an entirely team-based activity and I would like to thank every member of this team for their hard work, determined endeavour and pursuit of excellence.

Professor Louise Parker
**Director of PLERG**

PLERG Report compiled by
Susan Lee
Research Support Co-ordinator
May 2005

# The Paediatric and Lifecourse Epidemiology Research Group

**Back Row Left to Right**
Dr Julian Thomas, Dr Mark Pearce

**Middle Row Left to Right**
Dr Richard McNally, Mr Richard Hardy, Mrs Audrey Atkinson, Dr Judith Rankin, Dr Ruth Bell, Dr Caroline Relton, Professor Louise Parker, Dr M Tevfik Dorak, Dr Svetlana Glinianaia, Mrs Jane Salotti, Mrs Nor Aini Abdullah, Professor Ann Le Couteur, Dr Kathryn Parkinson, Dr Allan Colver, Mrs Donna Hammal, Miss Susan Lee

# Introduction

## Who we are

The Paediatric and Lifecourse Epidemiology Research Group (PLERG) was established in 2002 within the University's Department of Child Health. The Department became part of the newly formed School of Clinical Medical Sciences in August 2002 when the University undertook a major restructuring programme of its Department and Faculty structures.

PLERG brings together a range of people with common research interests from universities and hospitals in the North East and includes professionals from research, academic and clinical backgrounds.

We are situated mainly on Level 4 of the Sir James Spence Institute, Royal Victoria Infirmary, but some members of PLERG are based in the Medical School and other parts of the University and NHS.

**Sir James Spence Institute**

## What we do

As epidemiologists we are interested in the causes, the distribution and the control of conditions affecting health in populations. Work carried out by PLERG looks at the epidemiology relating to pre-natal and childhood environments as well as analysing the action and interaction of factors at different stages of the lifecourse.

Our research falls into two main areas: Paediatric Epidemiology and Lifecourse Epidemiology and we are pleased to present a summary of our work within this report.

# Staff List (Past and Present)

| | |
|---|---|
| Prof Louise Parker<br>Louise.Parker@ncl.ac.uk | Professor of Paediatric Epidemiology, Director of Group and Deputy Head of School<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffparker.htm |

## Academic Research Staff

| | |
|---|---|
| Dr Jean Adams[1]<br>J.M.Adams@ncl.ac.uk | Research Associate<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffadams.htm |
| Miss Kerry Anderson<br>Kerry.Anderson@ncl.ac.uk | Junior Research Associate<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffanderson.htm |
| Dr Terry Aspray<br>T.J.Aspray@ncl.ac.uk | Hon Clinical Senior Lecturer<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffaspray.htm |
| Mrs Kathleen Athey | Research Associate (left PLERG May 2004) |
| Dr Ruth Bell[1]<br>Ruth.Bell@ncl.ac.uk | Lecturer in Public Health<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffbell.htm |
| Dr David Campbell | First Assistant (left PLERG January 2005) |
| Dr Allan Colver<br>Allan.Colver@ncl.ac.uk | Reader in Community Child Health<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffcolver.htm |
| Professor Sir Alan Craft<br>A.W.Craft@ncl.ac.uk | Sir James Spence Professor of Child Health<br>http://www.ncl.ac.uk/medi/staff/profile/a.w.craft |
| Dr M Tevfik Dorak<br>Tevfik.Dorak@ncl.ac.uk | Principal Research Associate (joined PLERG in 2004)<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffdorak.htm |
| Dr Katherine Eastham | Clinical Research Associate<br>(MD student - left PLERG May 2004) |
| Mrs Gail Errington | Research Associate (left PLERG May 2004) |
| Dr Svetlana Glinianaia[1]<br>Svetlana.Glinianaia@ncl.ac.uk | Senior Research Associate<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffglinianaia.htm |
| Mrs Donna Hammal<br>D.M.Hammal@ncl.ac.uk | Research Associate (P-T PhD)<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffhammal.htm |
| Mrs Louise Hayes<br>Louise.Hayes@ncl.ac.uk | Research Associate (P-T PhD)<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffhayes.htm |

| | |
|---|---|
| Prof Steve Jarvis | Formerly Donald Court Professor of Community Child Health (Emeritus Professor since September 2004) |
| Prof Ann Le Couteur<br>A.S.Le-Couteur@ncl.ac.uk | Professor of Child and Adolescent Psychiatry<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffle-couteur.htm |
| Mrs Susan Leach<br>S.J.Leach@ncl.ac.uk | Research Nurse |
| Dr Paul McArdle<br>mcardlep@btinternet.com | Consultant Child/Adolescent Psychiatrist and Senior Lecturer |
| Dr Helen McConachie<br>H.R.McConachie@ncl.ac.uk | Consultant Clinical Psychologist & Senior Lecturer<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffmcconachie.htm |
| Dr Kathryn Parkinson<br>Kathryn.Parkinson@ncl.ac.uk | Senior Research Associate<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffparkinson.htm |
| Dr Mark Pearce<br>M.S.Pearce@ncl.ac.uk | Senior Research Associate<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffpearce.htm |
| Dr Tessa Pollard[2]<br>T.M.Pollard@Durham.ac.uk | Lecturer<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffpollard.htm |
| Dr Judith Rankin[1]<br>J.M.Rankin@ncl.ac.uk | Principal Research Associate<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffrankin.htm |
| Dr Caroline Relton<br>C.L.Relton@ncl.ac.uk | Senior Research Associate<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffrelton.htm |
| Mrs Jane Salotti<br>Jane.Salotti@ncl.ac.uk | Database Admin/Research Associate (P-T PhD)<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffsalotti.htm |
| Ms Anna Spencer<br>A.Spencer@ncl.ac.uk | Junior Research Associate<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffspencer.htm |
| Dr David Spencer<br>David.Spencer@nuth.northy.nhs.uk | Consultant in Respiratory Paediatrics |
| Dr Julian Thomas<br>J.E.Thomas@ncl.ac.uk | Clinical Senior Lecturer<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffthomas.htm |
| Dr Paul Tiffin<br>P.A.Tiffin@ncl.ac.uk | Specialist Registrar in Child and Family Psychiatry<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/stafftiffin.htm |

| | |
|---|---|
| Dr Elizabeth Towner | Senior Lecturer (left PLERG June 2004) |
| Dr Nigel Unwin<br>N.C.Unwin@ncl.ac.uk | Senior Lecturer<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffunwin.htm |
| Dr Richard Walker | Consultant Geriatrician/Honorary Senior Lecturer<br>Richard.Walker@Northumbria-healthcare.nhs.uk<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffwalker.htm |
| Mrs Brenda Welsh<br>B.E.Welsh@ncl.ac.uk | Junior Research Associate<br>http://www.ncl.ac.uk/medi/staff/profile/be.welsh |
| Ms Kirstie Whelan | Senior Research Associate (left PLERG July 2004) |
| Dr Martin White[1]<br>Martin.White@ncl.ac.uk | Senior Lecturer and Honorary Consultant in Public Health<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffwhite.htm |

**Support Staff**

| | |
|---|---|
| Mrs Audrey Atkinson<br>Audrey.Atkinson@ncl.ac.uk | PA to the Director/Deputy Head of School<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffatkinson.htm |
| Mrs Hilda Driscoll<br>Hilda.Driscoll@ncl.ac.uk | Secretary |
| Mr Richard Hardy<br>R.K.Hardy@ncl.ac.uk | Computing Officer<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/staffhardy.htm |
| Mrs Caroline Hodgson | Research Support Co-ordinator (left PLERG June 2004) |
| Mrs Katharine Kirton<br>K.E.Kirton@ncl.ac.uk | Secretary |
| Ms Susan Lee<br>S.E.Lee@ncl.ac.uk | Research Support Co-ordinator<br>http://www.ncl.ac.uk/plerg/Staff%20Pages/stafflee.htm |

[1]Member of Staff in the School of Population and Health Sciences

[2]Member of staff at the University of Durham

## Research Students

| | |
|---|---|
| Ms Nor Abdullah | PhD (Prof Louise Parker, Supervisor) |
| Ms Qi Xu (Helen) | MPhil (Prof Louise Parker, Supervisor) |
| Paschal Awah | PhD (Dr Nigel Unwin, Supervisor) |
| Mrs Mwenza Blell | MSc (University of Durham; Dr Tessa Pollard, Dr Mark Pearce, Supervisors) |
| Yu-Han Chen | MPhil (Dr Helen McConachie, Dr Jacqui Rodgers, Supervisors) |
| Dr Katharine Eastam | MD (Professor Louise Parker, Dr David Spencer, Supervisors) |
| Mr Rakesh Ghosh | PhD (Professor Tanja-Pless Mulolli, Dr Judith Rankin, Supervisors) |
| Miss Emma Honey | PhD (registered at University of Durham; Dr Helen McConachie, Dr Sue Leekam, Supervisors) |
| Dr Christine Jessen | MD (Dr Allan Colver, Supervisor) |
| Dr Laura Jones | MD (Prof Louise Parker, Professor Andrew Cant, Supervisors) |
| Mr David Whiting | PhD (Dr Nigel Unwin, Supervisor) |
| Ms Justine Mason | B.Med.Sci. (Dr Mark Pearce, Supervisor) |

# External Roles and Responsibilities

## Local, National and International Roles and Responsibilities

**Dr Jean Adams**

- External Editor for the McGill Journal of Medicine

**Dr Ruth Bell**

- Perinatal Mortality Survey Steering Group

**Dr Allan Colver**

- Co-ordinator of teaching of the Northumbria Healthcare Trust, Child Health Northumbria Base Unit
- Associate Editor, 'Current Paediatrics' (Elsevier)
- Member of the National Screening Committee (Child Health)
- Member of the Committee of the British Paediatric Surveillance Unit
- Member of the Executive Committee Survey of Cerebral Palsy in Europe (SCPE)

**Professor Sir Alan Craft**

- President - Royal College of Paediatrics and Child Health – 2003-2006
- Chairman Academy of Medical Royal Colleges – 2004-06
- Vice President of the Royal College of Paediatrics and Child Health 1998-2003
- Elected Member of Council Royal College of Paediatrics and Child Health 1996-98
- Chairman United Kingdom Children's Cancer Study Group 1992-94
- Chairman Medical Research Council Bone Sarcoma Committee 1989-96
- Member Cancer Therapy Committee, MRC (1989-96)
- Member of Management Board UK Case Control Study of Childhood Cancer (1992-present)
- Honorary President – Association for Children with Life-Threatening or Terminal Conditions and their Families
- Member of Council and Case Committee of MDU
- Member of the Professional Advisory Panel of the NHS Litigation Authority
- Co-Chairman European Intergroup Co-operative Ewings Sarcoma Study Group 1989-present
- President - International Paediatric Oncology Society (SIOP) 1999–2005 (Secretary General 1993-1999)

**Dr M Tevfik Dorak**

- Member of the British Society for Histocompatibility and Immunogenetics (BSHI)
- Member of the Genetical Society (UK) and European Association for Cancer Research (EACR)
- Member of the Editorial Board of Genes & Immunity
- Associate Member of the Northern Institute for Cancer Research, Newcastle University
- Visiting Research Fellow, Paediatric Epidemiology Group, Leeds University Medical School
- Consultant in NIH-Funded Project: Chromosome 6p21-24 markers in HIV-related Kaposi sarcoma (PI: Richard Kaslow, University of Alabama at Birmingham, USA)

**Dr Svetlana Glinianaia**

- Member of the Northern Multiple Pregnancy Register Steering Group
- Member of the Society for Social Medicine

**Professor Ann Le Couteur**

- Visiting Professor University of Durham 2002-present
- Member of the Steering Group University of Northumbria Autism Course 2002–present
- Child and Adolescent Mental Health 1996–present and Psychoanalytic Observational Studies Course 2002–present
- Academic Programme Director for Specialist Registrars in Child & Adolescent Psychiatry Training Scheme Northern Region 1996-present
- Honorary Senior Lecturer Institute of Psychiatry 1993–2002
- Honorary Consultant Tavistock Clinic, London
- Honorary Consultant Child & Adolescent Psychiatry, Newcastle, North Tyneside & Northumberland Mental Health NHS Trust 1995-present
- Member of Northern Regional Special Training Committee of Psychiatry 1996-present
- Member of Northern Group of Child & Adolescent Psychiatrists 1995–present
- Member of Child Health Executive Committee, University of Newcastle 1995–present
- Member of Royal College of Psychiatrists, ASD Working Party 2003–2004
- Member Child Psychiatry Research Society 1990–present (Treasurer and Honorary Secretary 1990–2003)
- Chair – Association for Child and Adolescent Mental Health (ACAMH formerly ACPP) 2003-2005; Executive Director, 1996–present; Member of Professional Advisory Group 2001–present.
- Chair – National Initiative for Autism: Screening and Assessment (NIASA) 2000–2003
- Medical Advisor National Autistic Society 2000–present
- Medical Advisor Contact a Family 2002–present
- Advisor All Party Parliamentary Group on Autism (APPGA) 2001–present
- Advisor to Children's NSF External Working Group for Disability 2002-2004
- Member of MRC Review of Autism Research 2001–2003
- Member of Steering Groups (FACTS 1998 – present; Fathers Plus 1998–present) Children North East
- Patron South Tyneside Autism Group 2002-present

**Dr Helen McConachie**

- Associate Editor, *Child: care, health and development* (from 1994)
- Visiting Professor, University of Northumbria at Newcastle, Centre for Clinical Psychology and Health Care Research (from June 2000)
- Honorary Senior Lecturer, Institute of Child Health, London, Neurosciences Unit (from April 1998)
- Co-Director (with Professor Naila Khan, Dhaka Children's Hospital, Bangladesh, and Professor Brian Neville, Institute of Child Health, London) of a British Council Academic Link Programme 1998-2004 on Promoting Child Development
- Editorial Board member, *Journal of Applied Research in Intellectual Disabilities*

**Professor Louise Parker**

- Editor-in-Chief of Pediatric Hematology and Oncology, USA [since 2000]
- Member of the United Kingdom Children's Cancer Research Group and Histiocytosis working groups
- Associate Editor of Pediatric Blood and Cancer
- Associate Editor of Pediatric Reviews
- Deputy Head of School of Clinical Medical Sciences
- Director of the Paediatric and Lifecourse Epidemiology Research Group
- Director of Child Health
- Associate Director of Research and Development, National Institute for Clinical Excellence [2003-2004]
- Member of University Medical and Dentals Appeal Panel 2001-2004
- Chairman, University Academic Selection Committee since 2003
- Member of the Royal College of Paediatrics and Child Health Research Executive
- Member of the Royal College of Paediatrics and Child Health Pharmacology Review Committee
- Member of the Patient Safety Research Group (NPSA)
- Member of COMARE (Committee on Medical Aspects of Radiation in the Environment)
- Member of the COMARE Transgenerational Effects Sub-committee
- Member of the UKCCSG Epidemiology and Registry Group
- Member of the International Epidemiological Association
- Member of the Expert Panel on Environmental Health Research by the EU
- Member of the UK Government Cabinet Office Women's National Commission Mentoring Network
- Member of WITEC (Women in Technology and Engineering)
- Appointed Governor, Gateshead Foundation Hospital Trust

**Dr Mark Pearce**

- Expert Member, Newcastle and North Tyneside Local Research Ethics Committee
- Editorial Board Member - Pediatric Hematology and Oncology
- Member of the International Epidemiology Association
- Member of the International Society for Developmental Origins of Health and Adult Disease
- Chartered member of the Royal Statistical Society

**Dr Judith Rankin**

- Secretary to the British Isles Network of Congenital Anomaly Registers (BINOCAR)
- Member of the RMSO Advisory Committee
- Member of the NorCAS Steering Group
- Member of the Multiple Pregnancy Steering Group
- Member of the Diabetic Survey Steering Group
- Member of the Public Health Research Group Executive
- Member of the Faculty Working Party for Contract Research Staff

**Dr Nigel Unwin**

- Medical Officer, World Health Organisation, Geneva, Switzerland

# Research Projects
# 2002 - 2004

# Paediatric Epidemiology

# Cancer Epidemiology

**Abstract**:

The Northern Region Young Persons' Malignant Disease Registry is a population based registry which has information on all young people, aged less than 25 years and resident in the North of England, diagnosed with cancer since 1968. The registry is located within the Newcastle Hospitals Trust, which is the regional specialist centre for cancer in children and adolescents and currently holds information on over 5,500 cases of malignant disease.

Data from the Registry have been used for a number of studies investigating the aetiology of cancer in children and young adults.

Studies completed during this period range from those presenting the incidence of and survival from childhood cancer to case-control studies investigating the potential effects of paternal occupational exposures on subsequent childhood cancer risk. Other interests in this area include the clustering and cross-clustering of childhood cancer incidence and the way in which some cancers may have an infectious aetiology.

A report from the Registry focusing on skin cancer found that both melanoma and non-melanoma incidence in young people has risen over the past 20 years, most likely due to increased ultraviolet exposure, and that thyroid tumours have increased in the region since the Chernobyl accident in 1985.

A case-control study found an increased risk of childhood leukaemia and non-Hodgkin's lymphoma (NHL) in those children whose fathers had jobs with high levels of contact with other individuals. These findings are consistent with the hypothesis of an infectious cause for childhood leukaemia and NHL and add to the evidence that such infections could be transmitted to children by adults.

In two separate studies, increased risks of childhood leukaemia and non-Hodgkin's lymphoma and decreased risks of brain and spinal tumours were found in areas with high levels of population mixing, most specifically where incomers had moved in from outside the region.

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**Principal Investigators**: Professor Louise Parker

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**Key Collaborators**: Professor Sir Alan Craft; Dr M Tevfik Dorak; Dr Richard Feltbower (University of Leeds); Mrs Donna Hammal; Dr Patricia McKinney (University of Leeds); Dr Mark Pearce

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**Project Staff**: Miss Claire Hamilton (Registry Secretary); Ms Lorna More (former Registry Secretary)

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**Funding**: North of England Children's Cancer Research Fund

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**Start and End Dates**: Ongoing

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**Publications associated with Project**:

Cotterill SJ, Wright CM, Pearce MS, Craft AW. Stature of young people with malignant bone tumors. *Pediatric Blood and Cancer* 2004; **42**: 59-63

Dickinson HO, Hammal DM, Dummer TJ, Parker L, Bithell JF. Childhood leukaemia and non-Hodgkin's lymphoma in relation to proximity to railways. *British Journal of Cancer*. 2003; 88: 695-8

Dickinson HO, Hammal DM, Bithell JF, Parker L. Population mixing and childhood leukaemia and non-Hodgkin's lymphoma in census wards in England and Wales, 1966-87. *British Journal of Cancer*. 2002; **86**: 1411-3

Dickinson HO, Nyari TA, Parker L. Childhood solid tumours in relation to infections in the community in Cumbria during pregnancy and around the time of birth. *British Journal of Cancer*. 2002; **87**: 746-50

Nyari TA, Dickinson HO, Hammal DM, Parker L. Childhood solid tumours in relation to population mixing around the time of birth. *British Journal of Cancer*. 2003; **88**: 1370-4

Nyari TA, Dickinson HO, Parker L. Childhood cancer in relation to infections in the community during pregnancy and around the time of birth. *International Journal of Cancer*. 2003; **104**: 772-7

Pearce MS, Parker L, Cotterill SJ, Gordon PM, Craft AW. Skin cancer in children and young adults: 28 years' experience from the Northern Region Young Person's Malignant Disease Registry, UK. *Melanoma Research.* 2003;**13**: 421-426

Pearce MS, Cotterill SJ, Parker L. Fathers' occupational contacts and risk of childhood leukemia and Non-Hodgkin lymphoma. *Epidemiology*. 2004; **15**: 352-356

**Paul O'Gorman Poster Prize – September 2004**
Donna Hammal "Paternal occupation as a risk factor for leukaemia and non-Hodgkin's lymphoma in children and young adults. A study from the north of England".

# North Cumbria Community Genetics Project DNA Bank

**Abstract**:

The North Cumbria Community Genetics Project (NCCGP) is a collaborative project between Newcastle University (PLERG and the Institute of Human Genetics) and Westlakes Research Institute. It is a biological sample bank containing samples from 7000 newborn babies and 3000 of their mothers collected at the West Cumberland Infirmary, Whitehaven, Cumbria, between 1996 and 2003. Samples include DNA, plasma and umbilical cord together with demographic and birth details, making this a very valuable resource for genetic epidemiologic investigation.

The NCCGP has contributed to over 20 collaborative research studies with groups from across the UK including studies into birth weight, fetal viability and cancer predisposition. Several new projects are currently underway. Further information and enquiries about potential applications of the resource can be made to Dr Caroline Relton.

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**Principal Investigator(s)**: Professor Louise Parker; Professor John Burn; Dr Jan Tawn (Westlakes Research Institute)

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**Collaborator(s)**: At *Newcastle University:* Professor Andy Hall, Professor Patrick Chinnery; Dr Steve Clifford; Dr M Tevfik Dorak

*Other Locations*: Professor Tim Bishop (Leeds); Dr Mike Stratton (Sanger Centre); Dr Barbara Jennings (UEA); Professor Andrew Hattersley (Exeter); Dr Ron Gray (Oxford)

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**Project Staff**: Dr Caroline Relton

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**Funding**: From the Westlakes Research Institute, Cumbria and other sources. Funding for maintenance of the sample repository is provided by the Life Knowledge Park.

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**Start and End dates**: 1 September 2003 – 31 August 2006

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**Publications associated with the project**:

Relton CL, Daniel CP, Hammal DM, Parker L, Tawn EJ, Burn J. DNA repair gene polymorphisms, pre-natal factors and the frequency of somatic mutations in the glycophorin-A gene among healthy newborns. *Mutation Research*. 2004; **545**: 49-57

Relton CL, Wilding CS, Laffling AJ, Jonas PA, Burgess T, Binks K, Tawn EJ, Burn J. Low erythrocyte folate status and polymorphic variation in folate-related genes are associated with risk of neural tube defect pregnancy. *Molecular Genetics and Metabolism*. 2004; **81**: 273-81

Wilding CS, Relton CL, Sutton M, Jonas PA, Lynch SA, Tawn EJ, Burn J. Thymidylate synthase repeat polymorphisms and risk of neural tube defects in a population from the Northern England. *Birth Defects Research Part A. Clinical and Molecular Teratology*. 2004; **70:** 483-485

# An Integrated Genetic and Epigenetic Research Programme to Investigate the Role of Folate in the Health of Children

**Abstract**:

Folate insufficiency in pregnancy is a risk factor for neural tube defects (NTDs) and other birth defects. Decreased maternal folate during pregnancy has also been associated with reduced infant birthweight. The influence of folate could be much greater than is currently appreciated due to its integral role in epigenetic marking of the genome.

The proposed programme of work focuses on 3 main aspects of paediatric health – NTD, preterm delivery and childhood obesity. Genetic and environmental factors contribute to the aetiology of each of these disorders, folate has been implicated in their aetiopathology and the underlying causes remain largely unresolved. Social patterning is also a feature of each of these disorders, with significantly increased prevalence in lower socio-economic groups.

The programme of work being undertaken uses molecular genetic techniques including genotype and DNA methylation analyses in association with genetic epidemiological methods to address paediatric health outcomes.

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**Principal Investigators**: Dr Caroline Relton

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**Collaborator(s)**: Professor John Mathers; Professor Louise Parker; Dr Mark Pearce; Mrs Donna Hammal; Dr Henk Blom (Nijmegen); Dr Ron Gray (Oxford)

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**Project Staff**: Dr Caroline Relton

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**Funding**: From the Westlakes Research Institute, Cumbria

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**Start and End dates**: 1 September 2003 – 31 August 2006

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**Publications associated with Project**:

Relton CL, Wilding CS, Jonas PA, Lynch SA, Tawn EJ, Burn J. Genetic susceptibility to neural tube defect pregnancy varies with offspring phenotype. *Clinical Genetics*. 2003; **64**: 424-8

Relton CL, Wilding CS, Laffling AJ, Jonas PA, Burgess T, Binks K, Tawn EJ, Burn J. Low erythrocyte folate status and polymorphic variation in folate-related genes are associated with risk of neural tube defect pregnancy. *Molecular Genetics and Metabolism*. 2004; **81**: 273-81

Relton CL, Wilding CS, Pearce MS, Laffling AJ, Jonas PA, Lynch SA, Tawn EJ, Burn J. Gene-gene interaction in folate-related genes and risk of neural tube defects in a UK population. *Journal of Medical Genetics*. 2004; **41**: 256-60

# The Regional Maternity Survey Office (RMSO)

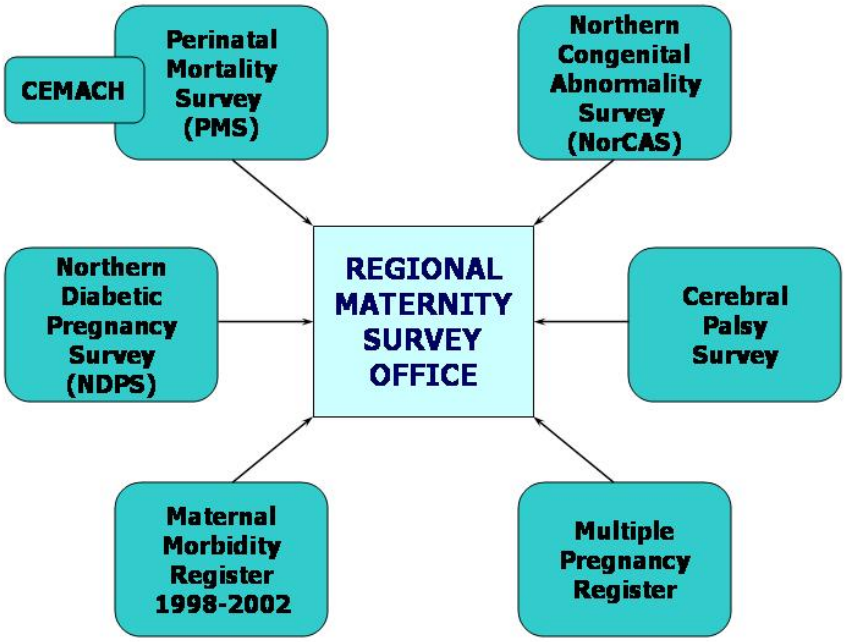
The Northern Regional Perinatal Mortality Survey was formally established in 1981 as a collaborative exercise between all the health districts in the former Northern Region, with the aim of studying perinatal mortality and its causes. In 1985, the Fetal Abnormality Survey (now the Northern Congenital Abnormality Survey - NorCAS) was established with the remit of obtaining data on congenital abnormality in the Northern Region. From 1993, the Regional Maternity Survey Office (RMSO) delivered the regional coordination function for the national Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI), including both data collection and running confidential enquiry panels. From April 2003, the RMSO has delivered these functions for the new Confidential Enquiry into Maternal and Child Health (CEMACH) which replaces CESDI.

In recognition of the importance of studying morbidity, the RMSO has also hosted a Multiple Pregnancy Register since 1998. The Regional Diabetic Pregnancy Survey (established in 1994) was incorporated into the RMSO during 1999. In addition the RMSO has hosted the North of England Collaborative Cerebral Palsy Survey (NECCPS) since 1995 (Figure 1.1).

Since April 2002, the RMSO has coordinated data collection for the Confidential Enquiry into Maternal Deaths which is now also incorporated into CEMACH.

Since January 2003, the RMSO has been the reporting route for the National Congenital Anomaly System (NCAS) and from mid 2004 has provided anonymised data for the European Surveillance of Congenital Anomalies (EUROCAT).

*Figure 1.1 The Surveys and Registers*




**Consent and confidentiality**

As a member of the British Isles Network of Congenital Anomaly Registers (BINOCAR), the Northern Congenital Abnormality Survey (NorCAS) obtained Section 60 Approval (Health and Social Care Act, 2001) to process data. Section 60 approval has also been obtained by CEMACH

for the national and regional components of its work. Patient consent is obtained for data collection for the Diabetic Pregnancy Survey and the NECCPS. Mechanisms for consent for the Multiple Pregnancy audit are being explored.

The RMSO Advisory Group was established in 2003 to address issues of consent and confidentiality in relation to the other surveys. The RMSO Advisory Group reports on its work in Chapter 13 (see Appendix (ii) for membership).

Data is processed at the RMSO within the parameters of its *Security and Confidentiality Policy.* The RMSO is British Standard 7799 compliant. Access to data is tightly controlled.

**RMSO outputs**

**The surveys and registers are utilised**:

- For local and regional audit in support of clinical governance in obstetrics, paediatrics and midwifery services across the region;
- As a platform for research into causes of deaths, anomalies and disability and research into service quality;
- As the regional component of national (and from 2004, international) surveillance programmes.

**In addition two new NHS objectives and performance targets require this data**:

- Infant Mortality Inequalities target;
- Monitoring and evaluation of antenatal screening programmes.

**The RMSO also provides the regional management function for CEMACH**

The RMSO provides regular feedback through this report and the annual meetings. There are annual meetings for four of the registers/surveys: PMS, NorCAS, NECCPS and the Diabetic Pregnancy Survey. These meetings are used to present work which has utilized the data and to debate controversial and topical issues.

# Perinatal Mortality in the Northern Region, 1982-2000: Contribution of Changing Maternal Risk Factors

**Abstract**:

Perinatal mortality in England and Wales has declined over the past 20 years, the rate has reached a plateau at a level higher than that in many other European countries. Perinatal mortality is known to be higher among teenage mothers, older mothers (>35 years), first births and multiple births. We hypothesise that the changing demographic profile of mothers has contributed to maintaining the static perinatal mortality rate in the Northern Region. The proposed retrospective cohort study will quantify the contribution of these factors (maternal age, parity and multiplicity) to the extended perinatal mortality rate in the Northern Region, overall and by major cause of death, and investigate the interaction of these risk factors. This study has the advantage of using data from a long-standing population-based register of late fetal loss, perinatal and infant deaths, the Northern Perinatal Mortality Survey.

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**Principal Investigators**: Professor Louise Parker, Dr Chris Wright, Consultant Paediatric Pathologist, RVI; Dr Judith Rankin; Dr Ruth Bell

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**Project Staff**: Dr Svetlana Glinianaia, Dr Mark Pearce, Dr Judith Rankin, Dr Ruth Bell

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**Funding**: The Newcastle University Hospitals Special Trustees

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**Start and End dates**: 1 April 2002 – 31 March 2003

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**Publications associated with Project**:

Pearce MS, Rankin J, Bell R, Glinianaia S, Parker L. Perinatal mortality: comparisons of rates are meaningless unless risk factor profile is adjusted. *Research in Midwifery and Perinatal Health Conference*, Birmingham, June 2003

Bell R, Rankin J, Pearce MA, Glinianaia S, Parker L. Perinatal mortality: the importance of adjusting for risk factor profile. *Society for Social Medicine, Edinburgh*, September 2003

Bell R, Glinianaia SV, Rankin J, Wright C, Pearce MS, Parker L. Changing patterns of perinatal death, 1982-2000: a retrospective cohort study. *Archives of Disease in Childhood*. 2004; **89**: 531-536

Rankin JM, Pearce MS, Bell R, Glinianaia SV, Parker L. Perinatal mortality rates: adjusting for risk factor profile is essential. *Paediatric and Perinatal Epidemiology*. 2005**; 19:** 56-58

# The Northern Congenital Abnormality Survey: A Collaborative Survey of Congenital Abnormalities in the Northern Region

**Abstract**:

Congenital anomalies are a significant cause of stillbirth and infant mortality accounting for around 1,000 stillbirths and 1,250 infant deaths in England and Wales annually. They also contribute to morbidity in the first years of life and beyond. The Northern Congenital Abnormality Survey (NorCAS), established in 1984, is an ongoing population based register of all congenital abnormalities arising within the population of the former Northern Region whether occurring in miscarriages, terminations of pregnancy or registered births, and whether diagnosed antenatally or later. Notification of cases is made from multiple sources, and all obstetric units in the Region contribute to the survey enabling high case ascertainment. It is managed by the Northern & Yorkshire Public Health Observatory in partnership with academic departments at Newcastle University. NorCAS is more complete than the National Congenital Anomaly System due to the strong local clinical network and the inclusion of cases resulting in termination of pregnancy. Over 50 research papers utilising NorCAS data have been published and the data has contributed to a number of local, national and international research projects. The abolition of Health Authorities renders the mechanism for funding NorCAS insecure and threatens its continuation. Five year funding would allow a period of stability, further development of the register and continued contribution to research.

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**Principal Investigators**: Dr Judith Rankin

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**Collaborator(s)**: Professor Louise Parker; Dr Martin Ward-Platt; Dr Tricia Cresswell; Professor John Burn

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**Project Staff**: Mrs Marjorie Renwick; Mrs Mary Bythell

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**Funding**: The Department of Health

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**Start and End dates**: 1 April 2003 – 31 March 2008

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**Publications associated with Project**:

Boyd PA, Armstrong B, Dolk H, Botting B, Pattenden S, Abramsky L, Rankin J, Vrijheid M, Wellesley D. Congenital anomaly surveillance in England - ascertainment deficiencies in the national system. *British Medical Journal* 2005; **330**: 27-31

Bell R, Rankin J, Donaldson LJ. Down's syndrome: occurrence and outcome in the north of England, 1985-99. *Paediatric and Perinatal Epidemiology*. 2003; **17**: 33-9

Lowry R, Steen N, Rankin JM. Water fluoridation, stillbirths and congenital abnormalities. Journal of Epidemiology and Community Health. 2003; **57**: 499-500

Rankin JM, Wright C. Survival of congenital anomaly sub-types is needed. *Archives of Disease in Childhood*. 2003; (Electronic Response)

http://adc.BMJJournals.com/CGI/Eletters/ArchDisChild;88/5/391#540

# Chronic Granulomatous Disease Registry

**Abstract**:

**Background**: Little is known about the extent of this very rare genetic disease in the British Isles. Therefore, in 2000, a collaborative project, funded by the CGD Research Trust, established a registry in the UK and Ireland.

The aims was to assess for any correlation between genetic variation and the pattern of illnesses seen in the disorder. The long-term goal is international collaboration with similar registries in Europe and the USA to decide on the appropriate long-term treatment for the different pattern of illnesses seen in patients.

Patients were identified by two methods. Firstly the CGD Research Trust circulated information on their website and in their newsletter. Patients were encouraged to contact their consultant or the research team for further information. Secondly all hospital consultants who were likely to be involved with the care of CGD patients were contacted and invited to notify the research team of any patients with the disease. Patient consent was sought via the treating consultant. Those who agreed to participate were sent a postal questionnaire on symptomology and quality of life with parents completing the questionnaire for younger children. A researcher also reviewed the patient's NHS notes. Comprehensive data on genetic and family history, clinical features, compications and treatments has been extracted from medical records,

The birth prevalence has been calculated as 1:147,000; still rare but much higher than was previously thought.

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**Principal Investigators**: Professor Louise Parker; Professor Andrew Cant

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**Collaborator(s)**: Dr TJ Flood – Newcastle General Hospital; Dr PJ McGrogan - RHSC Glasgow; Professor D Goldblatt, Professor A Thrasher and Mrs L Morton - Great Ormond Street

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**Project Staff**: Dr Laura Jones (MD student); Mrs Jane Salotti; Mrs Katharine Kirton; Mr Richard Hardy

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**Funding**: The Chronic Granulomatous Disorder Trust. http://www.cgd.org.uk/

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**Start and End Dates**: 1 September 2001 – 31 January 2007

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# Re-admission to Hospital within the First 28 Days of Life

**Abstract**:

**Aims**: To study the frequency and associations of early postpartum discharge and infant readmission to hospital.

**Methods**: Infants readmitted to hospital during the first 28 days of life in 1998 in the Northern Region of the UK were studied.

**Results**: A total of 4743 of 11,338 (42%) babies were discharged on or before the first postnatal day. Rates of early discharge varied significantly between hospitals. Infants <2500g at birth (adjusted odds ratio (AOR) 0.44, 95% CI 0.29 to 0.66), infants 35–37 weeks gestation at birth (AOR 0.65, 95% CI 0.49 to 0.86), and firstborn infants (AOR 0.09, 95% CI 0.08 to 0.10) were less likely to be discharged early. Women from more deprived areas were more likely to be discharged early (AOR 1.37, 95% CI 1.12 to 1.67). A total of 907 of 32,015 (2.8%) babies liveborn in the region were readmitted to hospital during 1998. Readmission rates varied significantly by hospital of birth but not by timing of discharge. Babies <2500g at birth (AOR 1.95, 95% CI 1.16 to 3.28) and babies born at 35–37 weeks gestation (AOR 1.72, 95% CI 1.15 to 2.57) were more likely to be readmitted. Breast fed babies were less likely to be readmitted (AOR 0.69, 95% CI 0.53 to 0.90). Infants initially discharged early were not more likely to be readmitted.

**Conclusions**: Early discharge occurred variably in the Northern Region in 1998. It is not associated with readmission to hospital. Breast feeding is associated with lower rates of readmission to hospital.

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**Principal Investigators**: Dr Sam Oddie; Dr Sam Richmond; Professor Louise Parker

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**Project Staff**: Mrs Donna Hammal

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**Funding**: The Newcastle Healthcare Charity

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**Start and End dates**: 1 March 2002 – 31 August 2002

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**Publications associated with the project**:

Oddie SJ, Hammal D, Richmond S, Parker L. Early discharge and readmission to hospital in the first month of life in the Northern Region of the United Kingdom during 1998: A case cohort study. *Archives of Disease in Childhood*. 2005. **90**: 119-124

# A Controlled Follow-up Study to Determine Whether Community Acquired Pneumonia Poses a Risk for the Development of Chronic Respiratory Disease in Childhood

**Abstract**:

**Introduction**: Few data are available concerning outcome for children admitted to hospital with radiologically confirmed community acquired pneumonia (CAP) in the UK, despite increasing evidence from community studies that long term sequelae may include deficits in lung function and asthma.

**Methods**: A controlled follow-up study investigated outcome for 103 children admitted to hospital with radiologically confirmed CAP (cases), after a median of 5.6 years. Each case was matched on sex and school class to a mean of 2 controls (n=248). Stage 1 of the assessment comprised a questionnaire which included medical history, clinical examination and spirometry. Children identified with potential chronic respiratory disease were referred for detailed respiratory assessment (Stage 2). Multiple regression was used to describe associations between explanatory variables, including CAP, and the outcome variables: $FEV_1$ percent predicted ($FEV_1$%), FVC percent predicted (FVC%), persistent cough and a doctor diagnosis of asthma.

**Results**: Amongst children of an atopic parent, cases had a 7.0% deficit in $FEV_1$% (95% CI -10.5, -3.2, p<0.001) and a 4.4% deficit in FVC% (95% CI -8.0, -0.78, p=0.017). This association was not observed amongst children of non-atopic parents. Cases were 2.4 times more likely (95% CI 1.02, 5.77, p=0.046) to have persistent cough at follow-up. Amongst children without pre-existing asthma of non-atopic parents, cases were 4.8 times more likely (95% CI 1.43, 16.34, p=0.011) to have a subsequent diagnosis of asthma at follow-up. This association was not significantly increased for children without pre-existing asthma of an atopic parent (OR 1.5, 95% CI 0.65, 3.48 p=0.340). Results were independent of known confounders.

**Conclusions**: CAP requiring admission to hospital is a significant risk factor for chronic respiratory disease in children. There is an urgent need to reconsider guidelines for a long term follow-up of these children, for which recommendations are currently lacking.

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**Principal Investigators**: Professor Louise Parker; Dr David Spencer

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**Project Staff**: Dr Katherine Eastham (MD student)

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**Funding**: The Sir Halley Stewart Trust and the Children's Research Fund

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**Start and End dates**: 1 March 2002 – 29 February 2004

# Langerhans Cell Histiocytosis Survey (in association with the BPSU)

**Abstract**:

A survey of children in the UK and Ireland is being undertaken over a two-year period in association with the British Paediatric Surveillance Unit (BPSU). LCH can affect many different parts of the body, most commonly the skin or bones. Little or no treatment may be required if only one system is affected and usually the disease regresses with time although this may take years. LCH can also be multi-system and is most serious in children under the age of two who have lung, liver, bone marrow or spleen involvement. In these cases children are treated on an international protocol (via the UK Children's Cancer Study Group (UKCCSG)). The survey which began in June 2003 has identified 48 cases to date including 29 males and 19 females. There are 34 cases with single system disease and 11 with multi-system disease (three are not yet known or have not been confirmed); two children have died.

As well as surveillance through the BPSU, the study group is also ascertaining cases through a complementary mailing system to other clinicians who may come across children with this disease - endocrinologists, dermatologists, radiologists, pathologists and orthopaedic surgeons. In addition, cases are being cross-referenced with those registered with the UKCCSG. Mailing of One-year Follow up questionnaires began in the summer and so far 9 have been returned.

The survey has also raised awareness of the number of adults with LCH, in which diagnosis and treatment is less well defined. This interest has resulted in clinicians meeting to discuss ways in which adult services may be coordinated in the future.

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**Principal Investigators**: Professor Louise Parker

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**Collaborator(s)**: Dr Kevin Windebank; Dr Vasanta Nanduri (Watford General Hospital); Dr Jon Pritchard (Royal Hospital for Sick Children) Edinburgh

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**Project Staff**: Mrs Jane Salotti

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**Funding**: Histiocytosis Research Trust http://www.hrtrust.org/

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**Start and End Dates**: 1 June 2003 – 30 June 2006

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**Publications associated with the Project**:

Population-Based Survey of Langerhans Cell Histiocytosis in Children in the United Kingdom and Eire: A Preliminary Report. Jane Salotti, Vasanta Nanduri, Kevin Windebank, Jon Pritchard, Louise Parker, University of Newcastle, Watford General Hospital, Royal Hospital for Sick Children, Edinburgh, in association with the British Paediatric Surveillance Unit. Abstract for Twentieth Annual Meeting of the Histiocyte Society, Stockholm. September 2004.

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British Paediatric Surveillance Unit Quarterly Bulletins 2003, 2004.
http://www.Bpsu.inopsu.com/publicat.htm

# Pre- and Post-natal Exposure to Particulate Matter and Pregnancy and Infant Outcomes: an Historical Cohort Study (1961-1992) [PAMPER]

**Abstract**:

Research on the potential impact of air pollution on human health has grown rapidly in recent years. There is now substantial evidence that short- and long-term increases in ambient air pollution are associated with increased mortality and morbidity in adults and children. The growing body of evidence suggests that exposure to ambient air pollutants, including particulates, can adversely affect fetal and infant health. This is of major public health concern as effects on fetal/infant development may impact on subsequent development and health with implications for health care, education and social services.

Using an historical cohort design, the aim of the proposed project is to investigate the strength and magnitude of the association between ambient particulate matter (black smoke) and birth outcomes and infant mortality. Data from detailed, complete delivery records (100,000+) for mothers resident in Newcastle will be linked with infant death registrations and daily black smoke data from 30 monitoring stations in operation in Newcastle between 1961-92. Exposure estimates will be derived for the maternal residence at the time of birth using mathematical modelling techniques. A space-time grid contour for black smoke exposure will be constructed using regression methods which will allow estimation of the maternal cumulative and peak exposures during each trimester of pregnancy. The association between maternal and infant exposure to black smoke and fetal/infant outcomes will be estimated using multiple logistic regression after controlling for relevant covariates.

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**Principal Investigators**: Professor Louise Parker; Dr Tanja Pless-Mulloli

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**Collaborator(s)**: Dr Mark Pearce; Dr Judith Rankin; Dr Martin Charlton; Dr Peter Diggle; Dr Richard Atkinson; Dr Fu-Meng Khaw; Mr Rakesh Ghosh

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**Project Staff**: Dr Svetlana Glinianaia; Mr Richard Hardy

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**Funding**: Wellcome Trust

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**Start and End Dates**: 1 March 2004 – 28 February 2007

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# Cryptorchidism and Hypospadias for the North of England

**Abstract**:

**Background**: There is evidence of an increasing incidence of cryptorchidism and hypospadias,[1-3] as components of the testicular dysgenesis syndrome,[4] the cause of which is unknown. However, complete datasets of such anomalies are few and far between, with reported trends often difficult to interpret due to incomplete ascertainment and varying inclusion criteria.[5] Hence, the absolute magnitude of any change in risk in male gonadal congenital anomalies is uncertain, as is the extent to which this is a global or local phenomenon.

The Northern Region has one of the highest quality congenital anomaly registers in Europe,[6-10] the Northern Congenital Abnormality Survey (NorCAS). NorCAS is a population-based register of all congenital anomalies occurring in those resident in the Northern Region whether diagnosed antenatally or not. Since 1985 it has registered over 16,000 cases of congenital anomalies among almost 700,000 births and terminations of pregnancy in the region. However, congenital anomalies of the male reproductive system, in particular cryptorchidism and isolated hypospadias are not registered.

**Aims**: The aim of this study is to explore the feasibility of constructing a retrospective register of cryptorchidism and hypospadias for the North of England, and to establish a framework for prospective notification.

**Study plan**: The study will determine sources of case ascertainment for cases of cryptorchidism and hypospadias throughout the Northern Region since 1990. The investigation will identify all paediatric surgical units that have treated cryptorchidism and hypospadias and assess the duration for which surgical records are available, their adequacy and in what form they are held. The scope of the records will also be investigated for details on factors such as birth weight, gestational age at birth, maternal age and parity. The possibility of linking the surgical record to the relevant delivery record will be investigated. Finally the study will assess the feasibility of establishing a routine prospective system of notification by surgeons to the register.

**Deliverables**: In the future, further applications will be made for the establishment of such a register that will provide the basis for an extensive research programme into the aetiology and changing trends of male testicular dysgenesis syndrome.

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**Principal Investigators**: Professor Louise Parker; Dr Mark Pearce

**Collaborator(s)**: Dr Judith Rankin; Dr Svetlana Glinianaia; Dr Bruce Jaffrey; Dr Tricia Cresswell; Dr Martin Ward-Platt

**Project Staff**: Nor Aini Abdullah (PhD student)

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**Funding**: Birth Defects Foundation

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**Start and End dates**: 1 June 2003 – 31 December 2005

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# Child and Adolescent Mental Health

**Abstract**:

This programme represents a series of inter-service, multi-professional partnerships between the Newcastle upon Tyne Hospitals NHS Trust and other partners including the Universities of Newcastle, Northumbria, Keele and Glasgow. It represents one of the few community child mental health programmes outside London. Key strands are:

- Epidemiology and secular trends in mental disorder. This work is based on a 1994 database, and data from a 1974 study of Newcastle children. We aim to conduct a further survey in 2004 to identify trends in the mental health and adjustment of Newcastle children. It presents a rare opportunity to measure changing patterns in childhood morbidity.

- Early intervention. What is the effectiveness of group therapy as an early intervention for at risk children? This is a randomised controlled trial, carried out in collaboration with a local authority and voluntary organisation as well as academic partners. A three-year follow up is included.

- Long-term risk and protective factors in mental health. This is a further analysis of the 1,000 Families database - a world class opportunity to study longitudinally the risk and protective factors measured in childhood on adult mental health.

- Pre-teen drug use. This is a survey of drug use, predisposing and protective factors among children in several cities, with Home Office funding and several universities collaborating, bringing in mental health and sociology academic skills.

- Youth drug use. This is a study of the pathways to and from problematic drug use among young people accessing designated drug services. This too has home office funding, and is a collaboration across sites and universities.

Overall aims of the programme are to study the current and evolving epidemiology of child mental disorders and risk behaviours, and the effectiveness of interventions against them. Its objectives are to:

1. Identify the scale and severity of mental and related disorders (including certain risk behaviours), comparing different centres and the same centre over time.
2. Develop and evaluate the effectiveness of interventions.
3. Incorporate insights learned into clinical practice through training at undergraduate and especially postgraduate levels, and to disseminate findings and their implications to other professionals including social services, voluntary sector and paediatric staff, as well as child and adolescent mental health services.

A new stream of work has recently begun tracing over 1000 children born locally in the year 2000 (The Gateshead Millennium Baby Study). The aims of the work are to answer questions concerning common adolescent syndromes such as eating disorders, conduct disorders and substance misuse; with the main focus being on environment, family and the neurodevelop-mental contributions to these disorders. It is hoped that the project will lead to a long-term study in the development of these children.

**Principal Investigators**: Dr Paul McArdle

**Collaborator(s)**:

**Start and End Dates**: April 2000 – May 2005

# Families and Communication Training and Support (FACTS) – Evaluation of Parent Group Training for Pre-School Children with Suspected ASD

**Abstract**:

This study was an evaluation of the 'More Than Words' training programme for parents of young children with autism spectrum disorders. 56 children aged 24 to 48 months were followed for up to two years. Their parents attended a three-month weekly group course to learn how to facilitate development of their child's social communication, led by speech and language therapists. Half received 'immediate intervention' and half were a 'delayed control' for the first 7 months of the study, depending on the starting date of the local courses.
We found that parents changed in the strategies they used in interaction with their child after attending a course, particularly the parents of children with the most severe autism. The children significantly increased their vocabulary and skills related to joint attention after their parents attended a course. Qualitative interviewing indicated a high level of parent satisfaction with the course.

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**Principal Investigators**: Professor Ann Le Couteur, Dr Helen McConachie

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**Collaborator(s)**: Children North East

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**Project Staff**: Dr Val Randle; Kay Ashley; Marie Sowter; Barry Ingham; Tim Diggle

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**Funding**: National Lottery Charities Board, 1999-2003; NHS Executive Research and Development, Northern and Yorkshire Region, 2000; Nuffield Foundation, 2001-02

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**Start and End dates**: 1 October 1999 – 30 September 2003

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**Publications associated with Project**:

Diggle T, McConachie HR and Randle V. Parent implemented early intervention for young children with autism spectrum disorder. In: *The Cochrane Library*, Issue 1. 2003; Oxford: Update Software.

Dixon L and Le Couteur AS. Early assessment and intervention with the 'More than Words' Hanen programme for parents of children with autism spectrum disorders. *Good Autism Practice*. 2003; **4(1)**: 29-34.

# International Molecular Genetic Study of Autism Consortium (IMGSAC)

**Abstract**:

Newcastle is one of five UK sites for this International Consortium. Multiplex and singleton families have been recruited and analysis of data is currently underway. Our team has special responsibility for behavioural phenotypic characterisation of the subjects. This has now led to the publication of Autism Diagnostic Interview (recognised as one of the gold standard diagnostic instruments in the field of ASD research. Ann Le Couteur now regularly reviews and revises translations of ADI-R into other languages including Icelandic, Japanese, Mandarin Chinese. Numerous Consortium Molecular Genetic papers have already been published and phenotypic and clinical academic papers are nearing completion.

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**Principal Investigators**: Professor Ann Le Couteur; Dr Helen McConachie

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**Collaborator(s)**: Professor Tony Bailey and Professor Tony Monaco, University of Oxford

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**Project Staff**: Dr Tom Berney

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**Funding**: European Commission, Medical Research Council and Wellcome Trust

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**Start and End dates**: 1 January 2000 – 30 April 2003

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**Publications associated with Project**:

Le Couteur AS, Lord C, Rutter M. Autism Diagnostic Interview Revised Manual. Western Psychological Services. 2003

Tiffin P, Le Couteur A. Pervasive Developmental Disorders, Chapter 8 in :*Seminars in Child and Adolescent Psychiatry 2nd Edition.* Ed Simon Gowers Gaskell, London. 2005

Newbury DF, Bonora E, Lamb JA, Fisher SE, Lai CSL, Baird G, Jannoun L, Slonims V, Stott CM, Merricks MJ, Bolton PF, Bailey Monaco AP, and the International Molecular Genetic Study of Autism Consortium. (Newcastle Site Le Couteur A, Berney T, McConachie H) 2002, *FOXP2* is not a major susceptibility gene for autism or specific language impairment. *American Journal of Human Genetics.* 2002; **70(5).** 1318-27

Beyer KS, Blasi F, Bacchelli E, Klauck SM, Maestrini E, Poustka A, and the International Molecular Genetic Study of Autism Consortium (IMGSAC) (Newcastle Site Le Couteur, A., Berney, T., and McConachie, H.) (2002). Mutation analysis of the coding sequence of the *MECP2* gene in infantile autism. *Human Genetics.* **111(4-5),** 305-9

Bonora E, Bacchelli E, Levy ER, Blasi F, Marlow A, Monaco AP, Maestrini E, and IMGSAC (Newcastle Site Le Couteur A, Berney T, and McConachie H) (2002). Mutation screening and imprinting analysis of four candidate genes for autism in the 7q32 region. *Molecular Psychiatry* **7**, 289-301

Bacchelli E, Blasi F, Biondolillo M, Lamb JA, Bonora E, Barnby G, Parr J, Beyer KS, Klauck SM, Poustka A, Bailey AJ, Monaco AP, Maestrini E, and International Molecular Genetic Study of Autism IMGSAC (Newcastle Site Le Couteur, A., Berney, T., and McConachie, H.) (2003).Screening of nine candidate genes for autism on chromosome 2q reveals rare non synonymous variants in the cAMP-GEFII gene. *Molecular Psychiatry* **8(11),** 916-924

Bonora E, *et al* and International Molecular Genetic Study of Autism (Newcastle Site Le Couteur A, Berney T, McConachie H.) (IMGSAC). Analysis of reelin as a candidate gene for autism. *Molecular Psychiatry. 2003;* **8 (10):** 885-92

Bonora E, *et al* and International Molecular Genetic Study of Autism (IMGSAC) (Newcastle Site Le Couteur A, Berney T, McConachie H.) Linkage to the AUTS1 locus and analysis of candidate genes for autism on chromosome 7q. *American Journal of Human Genetics.* 2003; Abstract 108

D'Adamo, P., Bacchelli, E., Blasi, F., Lipp, H.P., Toniolo, D., Mestrini, E., and the International Molecular Genetic Study of Autism Consortium (IMGSAC) (Newcastle Site Le Couteur, **A.,** Berney, T., and McConachie, H.) (2004). DNA variants in the human RAB3A gene are not associated with autism. *Genes Brain Behaviour* **3(2),** 123-4

Barnby G, Abbott A, Sykes N, Morris A, Weeks DE, Lamb J, Bailey AJ, Monaco AP, and the International Molecular Genetics Study of Autism Consortium (Newcastle Site Le Couteur A**,** Berney T, McConachie H.) (IMGSAC) (2004) Candidate gene analysis for autism on chr. 16p. *Journal of Human Genetics.* 2005; Submitted

Steyn B, Le Couteur A. Understanding autism spectrum disorders. *Current Paediatrics.* 2003; **13:** 274 – 278

Haq I, Le Couteur A, Autism Spectrum Disorder. *Medicine. 2004;* **32(8)**: 61-62

# Development of Parent-Reported Outcomes of Early Intervention for Children with Autism: the Well-being in Autism Index

**Abstract**:

The aim of the study is to develop and pilot a parent-rating scale which will capture changes in children's attention, awareness and physical symptoms. The WIAI will be used in studies of young children with autism, such as trials of gluten- and casein-free diet. There is currently no established measure which records all of the symptoms which parents report in anecdotal and open studies.

Following focus groups with parents, and review of the literature, a 48 item scale is being piloted with 30 parents of young children. The parent completes the WIAI and three other questionnaires about bowel symptoms, behaviour, and overall impression, on three occasions in total. The aim is to establish the internal consistency and test-retest reliability of the scale, and its stability over a 5 month period.

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**Principal Investigators**: Professor Ann Le Couteur; Dr Helen McConachie

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**Project Staff**: Mrs Susan Leach, Research Nurse

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**Funding**: Newcastle, North Tyneside and Northumberland NHS Mental Health Trust

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**Start and End dates**: 1 September 2004 – 30 June 2005

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# Establishment of a Registry of Children with Autistic Spectrum Disorder in North East England – Dasl$^{n}$e

**Abstract**:

Dasl$^{n}$e is a database of children with autism spectrum disorder living in the North East.

**The essential features of Dasl$^{n}$e are**:

It is an ongoing prospective database. The setting up phase requires a cross-sectional survey to identify all children with ASD; however, all the procedures are ongoing (to 18 years of age), and it will capture information on future children as they are diagnosed.

Families have been fully involved in all aspects of strategy, procedures and the detail of questionnaires. This process has been facilitated by three years starting up grant from the Northern Rock Foundation.

The database is multi-sectoral at the professional level. The responsibility for identifying cases in each district lies with a local co-ordinating group (drawn from paediatrician, educational psychologist, speech and language therapist, social worker, specialist teacher, and parent support group coordinator).

It is also multi-sectoral at strategic level. Its development phase was supported by Directors of Education, Social Services and Health, the University of Newcastle and Contact a Family. The statutory agencies have agreed to finance it after the development phase.

The primary aims of Dasl$^{n}$e are to identify all children with ASD and hence to assist local authorities, health services and voluntary bodies in planning their services for children with autism spectrum disorder. Reports on numbers of children and their broad needs will be made available and the project should allow families to be more involved in service planning.

It will also allow epidemiological analysis of the data to investigate, for example, trends over time or geographical variations to be a representative sampling frame for research studies.

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**Principal Investigators**: Dr Helen McConachie

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**Collaborator(s)**: Dr Allan Colver; Professor Ann Le Couteur; Professor Louise Parker

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**Project Staff** : Ms Anna Spencer

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**Funding**: The Northern Rock Foundation; participating local authorities

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**Start and End dates**: 1 November 2002 – 30 April 2006

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# The Development of Diagnostic Algorithms for Autistic Spectrum Disorders in Primary and Secondary School-Aged Children

**Abstract**:

This project will redefine, in the light of newly emerging diagnostic concepts, the diagnostic algorithms for autism and autism spectrum disorders using the ADI-R (autism diagnostic interview and the ADOS (autism diagnostic observation schedule)). Data using these two so-called gold standard research diagnostic tools will be collated from the seven UK sites collaborating on the study. Opportunities for cross validation will be provided using US datasets co-ordinated by Professor Cathy Lord, University of Michigan.

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**Principal Investigators**: Professor Ann Le Couteur

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**Collaborator(s)**: Professor Louise Parker, Dr Helen McConachie; 7 UK sites – Dr Gina Conti Ramsden (Manchester); Dr Anne Gilchrist (Aberdeen); Dr Fiona Scott (Cambridge); Professor Tony Bailey (Oxford); Dr Dorothy Bishop (Oxford); Dr Tony Charman (London); Professor Andrew Pickles (Manchester); Professor Eric Fombonne (Staffordshire); Professor Cathy Lord (USA)

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**Project Staff**: Mrs Donna Hammal

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**Funding**: The Health Foundation

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**Start and End dates**: 15 September 2003 – 14 September 2005

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# "Will it Ever Stop?" Repetitive Behaviours: A Neglected Area of Early Autism Research

**Abstract**:

This study had two aims. The first was to carry out a one-year longitudinal analysis of change or stability in the reported repetitive behaviours of 104 young children with communication disorders, including autism spectrum disorders. Though the level of repetitive behaviours is generally related to ability in the children, there was one subgroup of relatively able children with autism spectrum disorder who had unexpectedly high levels of repetitive behaviours. We found that parents report the impact and severity of problems diminish to an extent over the period of a year, though previous literature has suggested an increase. Parents described a range of coping strategies.

The second aim was to develop a more detailed interview about repetitive behaviours in autism with a pilot group of parents.

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**Principal Investigators**: Dr Helen McConachie; Professor Ann Le Couteur

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**Collaborator(s)**: Dr Michelle Turner (University of Durham)

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**Project Staff**: Miss Emma Honey

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**Funding**: Inge Wakehurst Trust

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**Start and End dates**: 1 January 2004 – 30 June 2004

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# Randomised Study of an Age-Paced Parenting Newsletter (Baby Express) in North Tyneside 2002-2006

**Summary**:

This controlled study is examining the effect of delivering an age-paced newsletter to the home of new parents in North Tyneside over the first two years of their child's life, on their understanding of and responses to infant emotional development and behaviour. The newsletter is delivered monthly for the first year and two-monthly in the second year when it is named 'Toddler Express', hence 18 newsletters are sent out.

The effects on the parents' expressed ability to handle the infant and their feelings about the baby are being explored by questionnaire in those who receive the newsletter, and in a control group. In the first and second years a selected group of parents will be videotaped during a play period to assess language use with the infant. More detailed interviews have also been carried out on a subgroup of parents including fathers, young mothers and ethnic minority parents to gain feedback on the newsletter content.

The aim of the study is to determine whether the sending of the Baby Express/Toddler Express will improve parent's understanding of and attitudes to their infant's emotional development, and thereby the management of their child's behaviour.

The study is now well underway, and 185 families were recruited and interviewed initially. There are 94 families in the intervention group who receive the newsletter. The control group, which has 91 families who do not receive the newsletter, but do receive incentives for taking part in the study.

At the initial interview, a set of questionnaires is completed by the families, and these are repeated when the baby is 1 year old and 2 years old.

*Questionnaires*

a) Initial demographic questionnaire: age, parity, employment, housing, car ownership and extended family support
b) Maternal Well-being: General Health Questionnaire
c) Parenting Daily Hassles Scale: understanding and attitudes to child's emotional development
d) Adult-Adolescent Parenting Inventory (APPI) Form B: self assessment of parenting
e) Parenting the 1st and 2nd Years: measuring the impact of Baby Express on parents. This will include experiences of child injury and attitudes to child care
f) Child Behaviour checklist

The questionnaires are scored and the information entered into a database. Similarly, the 'Parenting the 1st and 2nd year' questionnaires contain qualitative data and the information received is entered into the database for analysis.

*Outcome*

The outcome measures we are seeking are:

- High parental satisfaction with the content of the Baby/Toddler Express
- Less behavioural problems in the intervention group
- Improved parental attitudes as measured in APPI

- Fewer serious child accidental injuries in the intervention group
- A rich descriptive study of the decisions that parents take in relation to child care and their reasons

*Limitations*
The main limitations of the study will be as follows:

1. Attrition of numbers especially from the control group. We have already seen this happening and it is likely to increase. We are using incentives but may see low numbers in the control arm by the end of the study.
2. Convergence of results owing to contamination and new sources of information. As Toddler Express becomes well known, mothers in the control group may hear of it and obtain copies. Also, there is likely to be dissemination of information on parenting within North Tyneside where there is a lot of activity in early years initiatives.

*Analysis*
Analysis will be by comparison of numerical results in intervention and control groups and by qualitative analysis of the interviews. A new application has been made for a 3-year extension.

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**Principal Investigator**: Dr Tony Waterston

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**Collaborator(s)**: The Children's Foundation; Professor Louise Parker; Dr Helen McConachie; Ms Heather Welford; Ms Kate Welford; Dr Margaret Cook; Ms Eileen Birks; Mrs Donna Hammal; Ms Fran Sutherland

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**Research Staff**: Mrs Brenda Welsh, Dr Brigid Keane

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**Funding**: Family Support Unit (Home Office); Sutton Trust; Garfield Weston Foundation; Newcastle Education Action Zone

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**Start and End dates**: October 2002 – March 2005

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**Publications associated with the Project**:

Baby Express Pilot Study paper submitted to *Health Visitor Journal*

# Cerebral Palsy and Intrauterine Growth in Multiple Births: A Study Based on Data from the European Network of Cerebral Palsy Registers

**Abstract**:

Cerebral palsy is the most common cause of severe physical disability amongst children in developed countries. Twins are at much higher risk of neurological morbidity than singletons, and the proportion of twins among children with cerebral palsy has substantially increased in the last decade. Intrauterine growth retardation is known to be associated with cerebral palsy in singletons, but there is insufficient evidence of the association between intrauterine growth and the risk of cerebral palsy in twins, as previous research has been hampered by limited datasets. The proposed study has the advantage of using high-quality data from a European network of cerebral palsy registers with a large dataset, offering the unique opportunity to conduct a more detailed study of the relationship between cerebral palsy and fetal growth in twins, as judged by birth-weight for gestational age.

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**Principal Investigators**: Professor Louise Parker; Dr Svetlana Glinianaia; Professor Steve Jarvis; Dr Allan Colver

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**Collaborator(s)**: None

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**Project Staff**: Dr Svetlana Glinianaia

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**Funding**: Newcastle Healthcare Trust

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**Start and End dates**: 1 March 2003 – 30 November 2003

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**Publications associated with the Project**:

Glinianaia SV, Jarvis SN [on behalf of Surveillance of Cerebral Palsy in Europe Collaborative Group] Cerebral palsy and intrauterine growth in twins: a European multi-centre study. Twin Research 2004; **7(4)**: 349.

# Quality of Life and Childhood Disability

**Abstract**:

The study is examining the assessment of health-related quality of life in disabled children and their families. We are interested in the questionnaires used to measure health-related qualify of life and how well these work from the perspective of children and their families. These questionnaires are widely believed to prioritise the perspectives of lay people in policy considerations, their use has risen rapidly in recent years, and the information derived from them looks set to have an increasing influence. However, this information may be less useful if the questionnaires do not adequately cover the issues that matter to disabled children and their parents. Indeed, if not appropriately designed and used, these questionnaires may even have the potential to work against the priorities of disabled children. We would like to find out how the issues covered in the questionnaires compare with the children's and families priorities, and whether there is a need to refine the questionnaires or improve how they are used.

We are conducting in-depth interviews with 30 children aged 8-12 years and their parents. Families are being recruited through a separate and much larger study that has already been funded by the European Commission (SPARCLE). Children and their families have completed a health-related quality of life questionnaire as part of SPARCLE and told us whether or not they are interested in being interviewed. We use the returned questionnaires and other information to make sure we interview a group of children with a range of different experiences of life quality and from a range of different social backgrounds. We hope that in having children's perspectives as a central focus and including children with communication difficulties, our study will be useful and informative.

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**Principal Investigators**: Dr Bridget Young (University of Liverpool)

**Collaborator(s)**: Dr Kathryn Parkinson; Dr Allan Colver; Dr Mary Dixon-Woods (University of Leicester)

**Project Staff**: Ms Helen Rice

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**Funding**: Economic and Social Research Council

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**Start and End dates**: 1 September 2004 – 28 February 2006

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**Publications associated with Project**:

Colver A, Parkinson K. *et al*. SPARCLE – Study of participation of children with cerebral palsy living in Europe. *MAPI Research Institute*, 32, April 2004

# Study of the Participation of Children with Cerebral Palsy Living in Europe [SPARCLE]

**Abstract**:

Cerebral palsy is the most common cause of physical impairment in childhood and associated with cognitive and sensory impairments. There are 10,000 new cases a year in the EU and children with cerebral palsy continue to be seriously disadvantaged with respect to social relationships, education and employment prospects. The environment may hinder or promote participation and quality of life but it is not known which environmental factors should be promoted because they have rarely been evaluated against a well-defined outcome. Environmental factors are defined as the physical, social and attitudinal environment in which people live and conduct their lives and include such factors as legislation on access to buildings, social attitudes and norms, anti-discrimination legislation and transport design. Within any one locality or even country, such environmental factors are relatively constant and therefore it is difficult to study their influence. However by comparing different countries, significant associations may be identified between certain environmental factors and outcome. The aim of SPARCLE is to identify the environmental factors which, if improved, will yield the greatest benefits for children and their families. Such knowledge will inform EU policy in the health, educational and social sectors and generate protocols to optimise outcomes.

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**Principal Investigators**: Dr Allan Colver (UK)

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**Collaborator(s)**: Professor Eva Beckung (Sweden); Dr Jackie Parkes (Northern Ireland); Dr Jerome Fauconnier (France); Ms Vicki McManus (Ireland); Dr Susan Michelsen (Denmark); Dr Giorgio Schirripa (Italy); Dr Catherine Arnaud (France); Dr Ute Thyen (Germany)

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**Project Staff**: Dr Kathryn Parkinson (UK); Ms Kerry Anderson (UK); Ms Emma Hutchinson (UK); Dr Heather Dickinson (UK); Dr Malin Carlsson (Sweden); Mrs Ann Madden (N Ireland); Ms Ondine Pez (France); Dr Louise Gibson (Ireland); Mrs Eva Eriksen (Denmark); Dr Barbara Caravale (Italy); Ms Jude Canute (Italy); Ms Delphine Fenieys (France); Mrs Melanie White-Koning (France); Ms Heidi Kiecksee (Germany); Dr Betting Gehring (Germany)

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**Funding**: Commission of the European Community

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**Start and End dates** : 1 October 2002 – 30 June 2006

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**Publications associated with the project**:

Hammal D, Jarvis S, Colver A. Participation of children with cerebral palsy is influenced by where they live. *Developmental Medicine and Child Neurology*. 2004; **46:** 292-298

Mihaylov S, Jarvis S, Colver A, Beresford B Idenfication and descripton of environmental factors that influence participation of children with cerebral palsy. *Developmental Medicine and Child Neurology*. 2004; **46**: 299-304

Colver A, Parkinson K. *et al*. SPARCLE – Study of participation of children with cerebral palsy living in Europe. *MAPI Research Institute*, 2004; **32:** April 2004

# Life Expectancy in People with Cerebral Palsy

**Abstract**:

*Background*: Regional variation in survival among people affected with cerebral palsy has been observed, but has not previously been investigated in detail. In addition to true differences, variations in the methods and definitions used, completeness of ascertainment, and the role of potential confounding factors have all been proposed as possible explanations for these observed variations.

*Aims*: To assess the regional differences in survival of young people with cerebral palsy and the effect on survival of socio-economic differences after adjusting for variations in level of impairment and birth characteristics.

*Methods*: Survival patterns for young people with cerebral palsy were calculated using information from a collaborative database on birth characteristics, socio-economic status, and severity of cerebral palsy in young people born in five geographically defined areas in the United Kingdom, between 1980 and 1996, and on information provided by the relevant births and death register.

*Results*: There were 325 deaths among the 4007 cases of cerebral palsy identified. The proportion of affected children surviving to 20 years of age ranged from 85% (Merseyside and Cheshire, males) to 94% (North of England, males). Survival was influenced by birthweight and gestational age, number and severity of impairment, and deprivation status. Multivariate modelling showed that the severity of impairment had the biggest impact on survival, and that further contributions were made by birthweight and socio-economic status, but that after such adjustments, regional differences were no longer significant.

*Conclusions*: The number and severity of impairments are the best predictors of survival in young people with cerebral palsy. Socio-economic status makes additional contribution to the variation in survival after adjusting for severity of impairment and birthweight.

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**Principal Investigators**: Dr Jane Hutton (University of Warwick); Dr Allan Colver

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**Collaborator(s)**: Dr Parkes (Queens University, Belfast); Dr Kurinczuc (Perinatal Epidemiology Unit, Oxford); Dr Chalmers (Lothian Health Board, Edinburgh); Dr Platt (University of Liverpool)

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**Project Staff**: Dr Karla Hemming (University of Warwick)

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**Funding**: Medical Research Council

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**Start and End dates**: 1 October 2002 – 30 September 2005

# Development, Implementation and Evaluation of a National Injury Prevention Training Course

**Abstract**:

The Department of Health has provided funding to develop a national training course on injury prevention. The course has now been implemented on three occasions and for the first two courses the acceptability and effectiveness of the course was evaluated.

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**Principal Investigators**: Dr Elizabeth Towner

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**Collaborator(s)**: Dr M Hayes; Dr P Laidman

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**Project Staff**: Dr Therese Dowswell

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**Funding**: Department of Health

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**Start and End dates**: 1 September 1999 – 31 March 2003

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**Publications associated with the Project**:

Dowswell T, Towner E. Social deprivation and the prevention of unintentional injury in childhood: a systematic review. *Health Education Research* 2002; **17**: 221-37

Towner E, Towner J. UNICEF's child injury league table. An analysis of legislation: more mixed messages. *Injury Prevention* 2002; **8**: 97-100

Towner E, Dowswell T. Community-based childhood injury prevention interventions: what works? *Health Promotion International* 2002; 17: 273-84

# International Survey of Child Road Safety

**Abstract**:

This was a survey of the road safety practices and policies of 30 OECD countries. The study involved data collection and analysis of child pedestrian, cyclist and car occupant injuries, studies of exposure to injury risk and a questionnaire survey of transportation department personnel to determine which injury prevention measures, such as education, environmental modification and legislation had been implemented.

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**Principal Investigators**: Dr N Christie; Dr Elizabeth Towner; Dr H Ward; Dr S Cairns

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**Collaborator(s)**: Collaborative study with University of Surrey and University College London

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**Funding**: Department for Transport

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**Start and End dates**: 1 June 2002 – 1 June 2004

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**Publications associated with Project**:

Christie N; Cairns S; Ward H, Towner EM. Children's Traffic Safety: international Lessons for the UK. Road Safety Research Report No. 50, Department of Transport, London. 2004.

Christie N, Towner EM, Cairns S, Ward H. Children's Road Traffic Safety: An International Survey of Policy and Practice. Road Safety Report No. 47, Department of Transport, London. 2004.

# Evaluation of the National Child Pedestrian Training Pilot Project

**Abstract**:

This is the evaluation of the 'Kerbcraft' programme; a child pedestrian training programme which has been implemented in over 100 local authorities in England and Scotland. The Newcastle team has responsibility for three main strands of the study: designing and implementing a survey of volunteers; managing the behavioural assessment of children's skills improvement at the roadside and designing and implementing an in-depth investigation of the impact of the Kerbcraft Model in ten Case Study schools.

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**Principal Investigators**: Dr Elizabeth Towner

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**Collaborator(s)**: Professor Louise Parker; Jacobs Babtie

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**Project Staff**: Ms Kirstie Whelan

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**Funding**: Department for Transport, Local Government and the Regions

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**Start and End dates**: 1 August 2002 – 30 June 2006

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# Regional Life Skills Initiative Feasibility Study into the Establishment of Regional Safety Centre for Tyne and Wear

**Abstract**:

This research was commissioned by the Northern Regional Safety Initiative Steering Group to explore the feasibility of establishing a fixed-site, regionally based resource for safety education.

The objectives of the study were:

- To map the extent of injury prevention activities in Tyne and Wear and the contribution of different agencies.
- To solicit opinions from representatives of multi-agency groups in the area about the need for a "Life Skills Initiative" and what form this could take.
- To review briefly the literature on similar initiatives and to examine what other initiatives around the country comprise.
- To present a range of options at a seminar which can be debated so that some consensus proposal is achieved.

The study was conducted in the five districts of Tyne and Wear. One-to-one interviews were conducted with a snowball sample of fifty-two professionals representing agencies with an interest in life skills initiatives. A focus group discussion was held with pupils from Year 5, all of whom had visited "Safety Works" (a fixed-site resource centre) in the East end of Newcastle. Three site visits were made to safety centres located in Bristol, Glasgow and Milton Keynes.

The results of the interviews showed wide-held support for interactive safety events with all districts having run these in their local area. 96% of those surveyed were in favour of establishing a regional centre, 62% favoured a fixed-site resource as opposed to a mobile facility. No consensus was reached on where such a site would be located. Several sources of funding were suggested, in addition training courses e.g. Health and Safety and First Aid could provide a source of income-generation. Views were divided as to whether there should be a charge levied for use of the resource. A seminar was held in July 2003 to discuss the findings, and at subsequent meetings of the Regional Steering Group it was agreed to progress the initiative with the initial focus being on preventing unintentional injury and targeted mainly toward school-aged children.

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**Principal Investigators**: Dr Elizabeth Towner

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**Collaborator(s)**: None

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**Project Staff**: Mrs Kathleen Athey; Mrs Gail Errington

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**Funding**: Health Action Zone

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**Start and End dates**: 1 January 2003 – 31 July 2003

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**Publications associated with the Project**: Report produced in July 2003

# Kerbcraft Road Safety Training Video

**Abstract**:

**Background**:

*The National Network of Child Pedestrian Training Pilot Schemes*
The Department for Transport are currently funding 103 road safety training schemes within Local Authorities in England between 2002 and 2006. Each scheme is based on the "Kerbcraft Model" (Thomson, 1997[1]; Thomson & Whelan, 1997[2]) where a scheme Co-ordinator recruits and trains adult volunteers from the local school/community to train 5-7 year old children in 3 practical road safety skills at the roadside. These 103 schemes form the National Network of Child Pedestrian Training Pilot Schemes, which is being managed by MVA and independently evaluated by Jacobs Babtie and the University of Newcastle upon Tyne (now at University of West of England, Bristol).

Every scheme co-ordinator within the National Network receives training through MVA, enabling them to then recruit and train volunteers in each of their participating schools. The volunteers are then assisted in delivering training to children in the target age range (Year 1 and 2). This process is known as 'cascade training' and is an established and successful method of facilitating procedural skills acquisition. However, where more complex tasks are involved, the key messages can sometimes be diluted across the levels of implementation, resulting in less efficient training at ground level.

*Response to challenges of Cascade Training*
Ongoing monitoring and evaluation of the National Network has identified a potential for erosion of the key training elements and ethos of the Kerbcraft model as it moves through the stages of the cascade process.

Feedback from scheme co-ordinators to MVA indicated that a training video for volunteers may help to counteract this erosion process, whilst also providing an opportunity to facilitate and standardise the training delivered to volunteer trainers across the National Network schemes.

*Reduction in casualty rates*
The production of the training video was not intended to directly link to any outcome measuring reduction in casualty rates. However, by improving standards of training across the National Network, we anticipated an indirect impact on two of the key outcome measures from the National Network evaluation:

Skills Assessment: improvements in children's roadside behaviours after training
Parental Survey of Accident Involvement: a lower accident involvement of trained children in comparison to a matched control group

**Aims and Objectives**:

[1] THOMSON J. (1997) *"Kerbcraft: smart strategies for pedestrian safety"* Department for Transport.
[2] THOMSON J. & WHELAN KM. (1997) *"A community approach to road safety education using practical training methods: The Drumchapel report"* Department for Transport Road Safety Research Report No. 3.

The project proposal outlined the development and production of a Volunteer Training Video which would not only seek to redress the potential for erosion of key Kerbcraft training messages within the National Network, but also provide a lasting and highly adaptable resource for future education, promotion and implementation of practical road safety training for primary school children.

*Immediate Aims*

1. Produce a practical road safety training video for use by Kerbcraft Co-ordinators in recruiting, training and maintaining volunteer trainers.
2. Use the video to encourage consistency in the uptake and implementation of key messages in the Kerbcraft model across all schemes in the National Network of Child Pedestrian Training Pilot Schemes.
3. Enhance the success of the National Network Schemes by improving the quality of road safety training received by children in participating schemes.

*Long-term Aims*

1. The video would become a key part of a resource pack which would enhance the implementation of Kerbcraft after the National Network funding expires in 2006.
2. The video would be available to policy makers, academics, Local Authorities and other practitioners as an educational and promotional tool.
3. The video would include guidance on using established assessments of children's behavioural change after training in Kerbcraft skills, thus providing an evaluation tool for future users of the Kerbcraft model.

*Objectives*

To produce a video which will:

1. Illustrate best practice in road safety training at the roadside.
2. Reinforce key elements of each Kerbcraft skill, paying special attention to encouraging appropriate dialogue style; and illustrating the stages of the behavioural modelling process.
3. Illustrate Best Practice in conducting training at the roadside and providing guidance to volunteer trainers on children's behaviour management.
4. Provide examples of how best to use different road layouts and environments for successful training.
5. Provide an appropriate resource which is representative of the areas targeted by the National Network.
6. Reinforce the key training messages of the Kerbcraft model and minimise the potential for dilution of these messages through cascade training.

**Conclusions**:

The key aims and objectives of the project were met within budget and timeframe:

1. 150 videos were distributed to National Network Kerbcraft Co-ordinators in April 2004.
2. A successful partnership is working between University of Newcastle and MVA.
3. Remaining copies of the video have been sent to relevant external practitioners, academics, organisations and policymakers to promote National Network and Kerbcraft.
4. Preliminary feedback from co-ordinators indicates 100% uptake of video as successful training tool for volunteers. Many co-ordinators have, in fact, asked for additional copies and a further fifty have been ordered (using different funds) to satisfy additional demand.

5. Further impact of video will become apparent within timescale of National Network from MVA monitoring processes and Evaluation outcomes.

**Future areas of development**:

Future development of a comprehensive resource pack for co-ordinators based around the video – funding allocated to MVA team from Department of Transport Challenge Fund (April 2004).

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**Principal Investigators**: Ms Kirstie Whelan

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**Collaborator(s)**: Lisa Hartley (Independent); Carry Stephenson (MVA); Dr Elizabeth Towner (Department of Child Health, University of Newcastle upon Tyne)

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**Project Staff**: Ms Kirstie Whelan

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**Funding**: Department for Transport

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**Start and End dates**: 1 May 2003- 28 February 2004

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**Publications associated with the Project**:

Poster presentation at the 7th World Conference on Injury Prevention and Safety Promotion, Vienna, 6-9 June 2004. “The Kerbcraft Road Safety Training Video”.

Final Project Report to the Department of Transport – available from the Department of Transport on request (not published).

# Laser Schemes

**Abstract**:

The LASER study (Learning About Safety by Experiencing Risk) is an initiative funded by RoSPA (Royal Society for the Prevention of Accidents). LASER aims to develop skills in primary school-aged children which will enable them to make choices and informed decisions in relation to their own safety and the safety of others. Children learn how to stay safe by engaging in a series of interactive scenarios designed to illustrate situations where safety is an issue – for example when crossing a road, or in the event of a house fire. The concept is based on agencies working in partnership, across the public and private sectors.

As part of the project, the University of Newcastle was commissioned to develop an evaluation toolkit, providing a brief background as to the importance of evaluation along with a selection of methods and resources for the evaluation of LASER schemes.

The toolkit was launched at a national conference along with the study report in October 2003 and is available to purchase from RoSPA.

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**Principal Investigators**: Mrs Kathleen Athey

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**Collaborator(s)**: None

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**Project Staff**: Mrs Kathleen Athey; Mrs Gail Errington; Dr Elizabeth Towner

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**Funding**: Royal Society for the Prevention of Accidents (RoSPA)

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**Start and End dates**: 1 August 2003 – 31 October 2003

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**Publications associated with the Project**:

LASER report (RoSPA) containing chapter produced by University of Newcastle – an evaluation toolkit.

# Evaluation of the WHOOPS Introductory Certificate in Home Safety and Voluntary Training Course

**Abstract**:

*Background*: The "WHOOPS!" Child Safety Project was set up in March 2000 in Gateshead, Tyne & Wear with the aims of raising awareness of childhood unintentional injuries amongst parents, carers and children themselves, and reducing the impact of injury through basic first aid training for adults and older children. In August 2003 a volunteer training manager was appointed by the WHOOPS! Project to train local people in injury prevention and to build local capacity in the field. This report summarises the evaluation of the training programme, which took place between October 2003 and January 2005.

*Aim of the pilot study*: To Evaluate The Effectiveness Of The WHOOPS Volunteer Training Programme.

*Objectives*:

- To document the processes involved in recruiting parents and carers to the volunteer training programme.
- To assess changes in volunteer's levels of knowledge of relevant safety issues before and after the course.
- To obtain feedback from volunteers on the acceptability and appropriateness of the training course content and course materials.
- To assess the extent to which the objectives of the training course have been achieved.
- To assess added value of the training course for volunteers involved.

*Methods*: The sample included all volunteers involved in the pilot course.
A range of different methods was used to obtain data from trainee volunteers before, during and after the pilot course: One-to-one interviews or telephone interviews, Pre-test/post-test quizzes (prepared by WHOOPS team) and a Questionnaire survey.

Evaluation took place in four stages:

Stage 1: Pre-course evaluation November/December 2003. This included telephone interviews and a safety quiz administered to all trainees.

Stage 2: Mid – course evaluation: February 2004. The safety quiz and questionnaires were repeated.

Stage 3: Post course evaluation: March/April 2004 One-to-one interviews were carried out during the final week of the course, using a semi-structured interview schedule. Interviews also took place with trainees who had dropped out of the course.

Stage 4: Post course evaluation 12 months on: Nov/Dec 2004 Volunteers who had completed the pilot training course were interviewed again twelve months after they had been recruited.

The ten-week Introductory Certificate in Home Safety and Voluntary Training Course was facilitated by the WHOOPS Volunteer Training Manager and accredited (NVQ level 1) by Gateshead College. The course covered home safety awareness and training delivery skills.

*Results*: Eleven women attended a course induction day and nine enrolled on the course which commenced in January 2004. Seven completed the training. When interviewed twelve months after the start of the course all reported that they had passed on safety messages to others within their community on a formal or informal basis, although one volunteer had obtained paid work and therefore would not be working as a volunteer in the future. The results of the evaluation were fed back to the volunteer manager during the evaluation so that gaps in trainees' knowledge could be addressed.

Results of the evaluation demonstrate that the objectives set at the outset of the pilot course had been met. Outcomes of the course anticipated by prospective volunteers had been realised, in that home safety awareness levels were increased resulting in safer home environments, new friendships had been made and volunteers were given necessary skills to enable them to cascade home safety messages to family, friends and other people in local communities. Subsequent courses are now up and running or in the planning stage.

*Conclusion*: The main lessons learnt during the evaluation are: a personal approach to recruitment by the WHOOPS team is recommended and barriers such as concerns related to childcare and travel problems for potential volunteers need to be addressed. The current practice of encouraging volunteers to utilise their own training styles and practices at their own pace demonstrates the value that WHOOPS places on the role of each volunteer and will encourage individuals to remain working as volunteers in the future. The idea of developing a higher-level course has the approval of trained volunteers and would serve to include a number of additional issues highlighted within the evaluation. Once a core group of volunteers has been established, a higher-level course could serve to update and enhance volunteers' skills and safety knowledge. Overall the Volunteer Training Course was highly successful, recruiting and retaining committed volunteers, who have been motivated sufficiently to train large numbers of others within the borough.

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**Principal Investigators**: Mrs Kathleen Athey

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**Collaborator(s)**: None

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**Project Staff**: Dr Elizabeth Towner

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**Funding**: The Children's Foundation

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**Start and End dates**: 1 October 2003 – 31 January 2005

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# Evaluation of the Dealing with Disadvantage Project

**Abstract**:

This has now been renamed the Neighbourhood Road Safety Initiative. It is a national demonstration project, funded by the Department for Transport in 15 local authorities in North West England and the Midlands. The Department for Transport has provided resources to stimulate the implementation of injury prevention interventions in deprived wards and the evaluation focuses on the effectiveness of the intervention on injury outcomes and impacts. Particular focus is placed on partnership working.

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**Principal Investigators**: Dr Elizabeth Towner; H Ward; N Christie; R Lyons; M Hayes

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**Collaborator(s)**: University College, London; University of Surrey; University of Wales at Swansea; Child Accident Prevention Trust

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**Project Staff**: None

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**Funding**: Department for Transport

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**Start and End dates**: 26 January 2004 – 30 June 2008

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# Evidence and Guidance Collaborating Centre Prevention and Reduction of Accidental Injury in Children and Young People, aged 0-24 years

**Abstract**:

The aim of the Collaborating Centre on Accidental Injury is 'to provide the very best current evidence and practice-based knowledge about the reduction of inequalities in health in the field of accidental injury prevention to health professionals, the public and policy makers'. The Centre is conducting work in three main areas: Evidence Reviews/ Briefings summarising the evidence from effectiveness studies in the field, Effective Action Briefings which provides action-based knowledge and translates the evidence into practical guidance and an Information Service.

[The project continues with Gail Errington and Kathleen Athey based in the Centre for Health Services Research]

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**Principal Investigators**: Dr Elizabeth Towner; Dr M Hayes; Mrs Gail Errington

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**Collaborator(s)**: None

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**Project Staff**: Mrs Gail Errington; Mrs Kathleen Athey

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**Funding**: Health Development Agency

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**Start and End dates**: 1 March 2004 – 30 June 2004

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# Health Evidence Network Synthesis: What Works in Preventing Unintentional Injuries in Children aged 0-14 years and Older Adults, aged 65 years and over?

**Abstract**:

This project was a synthesis of existing reviews in the area and examined what works in the prevention of unintentional injuries in two age groups: children and older people.

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**Principal Investigators**: Dr Elizabeth Towner

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**Collaborator(s)**: None

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**Project Staff**: Mrs Gail Errington

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**Funding**: World Health Organisation (European Office)

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**Start and End dates**: 11 September 2003 – 31 December 2003

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**Publications associated with the project**:

Towner E, Errington G. What works in preventing unintentional injuries in children aged 0-14 years and older adults aged 65 years and over? A synthesis prepared for the World Health Organisation, Regional Office for Europe (web based publication). *Health Evidence Network* 2004.

# Models of Paediatric Services in Other Countries

**Abstract**:

This short study, exploring models of paediatric services in Western European countries, Australia, New Zealand and Canada, was commissioned jointly by the UK NHS Confederation and the Royal College of Paediatrics and Child Health. The objectives of the study were to compare and contrast organisational aspects of the provision of paediatric care in the UK with that in some European countries and elsewhere. In particular, the aims were to understand differences in provision of acute out-of-hours services and the structure of care in rural and isolated areas.

The study used three main data sources: telephone interviews using structured questionnaires, published material, and national and international organisations. Telephone interviews were conducted for a paediatric perspective with 21 informants from 16 participating countries (including UK) of comparable economic status. Summary information for each country was compiled from the sources above and some preliminary comparisons of the data were made:

1. The general population structure for the centres involved in the study.
2. Type of health service by country.
3. The type of health services organisation, e.g. regional vs national
4. Who delivers primary paediatric health care, e.g. GPs vs paediatricians
5. The type of payment, if any, for paediatric services and the method of payment
6. Which staff are on duty out of office hours and which primary care physicians double up as emergency providers
7. Urban and rural differences in countries

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**Principal Investigators**: Professor Louise Parker

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**Collaborator(s)**: Dr Mitch Blair, Consultant Reader in Paediatrics and Child Public Health, Imperial College, London

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**Project Staff**: Mrs Jane Salotti; Dr Svetlana Glinianaia

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**Funding**: NHS Confederation and Royal College of Paediatrics and Child Health

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**Start and End dates**: 1 December 2002 – 31 March 2003

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**Publications associated with the Project**:

An interim report for the NHS Confederation. Models of Paediatric Services in other countries (MOPS).

# Carbon Isotope Breath Analysis in Tests of Gastrointestinal Function in Children

**Abstract**:

This grant allowed the purchase of an automated breath carbon analyser (ABCA), which has been installed in the Sir James Spence Institute of Child Health, Royal Victoria Infirmary. Stable isotope breath tests (which are not radioactive) represent an ideal non-invasive means of investigating gut function in children of all ages. Our group has pioneered the use of the [13-C] urea breath test for the diagnosis of gastric *Helicobacter pylori* infection in epidemiological studies amongst children aged less than two years. These studies have all taken place at the Medical Research Council's Tropical Medicine Research Centre in The Gambia, West Africa, and samples have been analysed in Newcastle.

Key findings from this work are:

- *Helicobacter pylori* colonisation usually takes place during the first year of life in developing countries, and is a more dynamic process than had been anticipated
- Early *Helicobacter pylori* colonisation is associated with subsequent infant growth faltering
- Specific maternal milk antibodies protect infants from colonisation
- Transmission of infection is not enhanced by flies

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**Principal Investigators**: Dr Julian Thomas

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**Collaborator(s)**: Professor Andrew Prentice, Head of Nutrition Group, London School of Tropical Medicine and Hygiene; Dr Richard Adegbola, Director of Infectious Diseases Research Programme, Medical Research Council Laboratories, The Gambia; Professor Lawrence Weaver, Professor of Child Health, University of Glasgow; Professor Doug Berg, Professor of Microbial Genetics, Washington University in St. Louis, USA.

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**Project Staff**: Dr Julian Thomas

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**Funding**: The Children's Foundation

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**Start and End dates**: 10 December 2002 – 9 December 2003

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**Publications associated with Project**:

Thomas JE, Dale A, Bunn JEG, Harding M, Coward WA, Cole TJ, Weaver LT. Early *Helicobacter pylori* colonisation: the association with growth faltering in The Gambia. *Archives of Disease in Childhood*. 2004; **89**: 1145-54

McNulty SL, Mole B, Dailidiene D, Segal I, Ally R, Mistry R, Secka O, Adegbola RA, Thomas JE, Lenarcic EM, Peek RM, Jr., Berg DE, Forsyth MH. Novel 180- and 480-Base-Pair Insertions

in African and African-American Strains of *Helicobacter pylori. Journal of Clinical Microbiology*, 2004; **42(12)**: 5658–5663

Thomas JE, Bunn JEG, Kleanthous H, Monath TP, Harding M, Coward WA, Weaver LT. Specific Immunoglobulin A Antibodies in Maternal Milk and Delayed *Helicobacter pylori* Colonization in Gambian Infants. *Clinical Infectious Diseases.* 2004; **39**: 1155–60

Allen, SJ, Thomas, JE, Alexander, NDE, Bailey, R, Emerson, PM. Flies and *Helicobacter pylori* infection. *Archives of Disease in Childhood*; 2004; **89**: 1037-8

Jones RT. Evaluation of 13C-urea breath test and faecal antigen immunoassay to detect *Helicobacter pylori* infection in Gambian infants. Dissertation for degree of M.Res., awarded with distinction, 2004. Supervisor: Dr JE Thomas.

# Children with Long-Term Disability in the former Northern & Yorkshire NHS Region – a Scoping Study for the North East Public Health Observatory

**Abstract**:

The purpose of this study was to describe the population of children with long-term disability in the Northern and Yorkshire NHS Region against a background of concern about the overall quality of child health information. The study was commissioned in awareness of the rising prevalence of children and young people with severe disability and complex needs due to a combination of factors including:

- Increased survival of premature babies and those born with genetic disorders or congenital anomalies
- Increased survival of children after severe trauma or infection
- Increased incidence of multiple births leading to premature and low birthweight babies
- Increase in the number of older mothers leading to increase in some congenital anomalies

These factors are to an extent balanced by a drop in the total numbers of births in the region and the impact of antenatal screening and termination of pregnancy. However the net impact is a rise in the prevalence and actual numbers of children and young people in the region with complex needs. Planning services for these children requires a clear picture of their needs,

The study looked at information held by social services, health services and academic departments. Interviews were held with key informants including staff in local authorities, special needs coordinators, community and hospital paediatricians, social service managers for children with disability and staff in the voluntary sector. Legislation, medical literature and health reports were reviewed. Further interviews took place with children with disability register coordinators in each local authority. National sources of data were also reviewed and the interim results of the survey were presented at two workshops at which delegates made many relevant contributions.
A summary of findings, discussion and recommendations for action can be found in the report below or on the North East Public Health Observatory (NEPHO) website.

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**Principal Investigators**: Professor Louise Parker

**Collaborator(s)**: Dr Tricia Cresswell (North East Public Health Observatory); Dr Jane Lothian (North Tyneside Primary Care Trust)

**Project Staff**: Mrs Jane Salotti, Professor Steve Jarvis, Mrs Donna Hammal, Dr Allan Colver

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**Funding**: Northern and Yorkshire Public Health Observatory

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**Start and End Dates**: 20 September 2001 – 19 September 2002

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**Publications associated with the Project:**

Children with long-term disability in the former Northern and Yorkshire NHS Region. North East Public Health Observatory, March 2004. http://www.nepho.org.uk

# How do Toddlers' Feeding Behaviour Problems Relate to Growth and Earlier Feeding

**Abstract**:

Although most infants feed easily and grow well, 5% show some growth faltering. Sustained growth faltering, often known as failure to thrive (FTT) typically begins very early in life and is associated with disordered feeding; but it is not yet known whether this is innate in FTT children, or whether it is the result of the infant's early feeding experiences, which produce an aversion to food. The Millennium Baby Study aimed to determine the extent to which failure to thrive stems from problems in the child, or the family, or an interaction of both.

Past research investigating the antecedents of failure to thrive has depended on retrospective accounts, which introduces problems such as referral bias and inaccurate recall. The Millennium Baby Study, on the other hand, is a prospective population study where a total of 1029 infants and their families were recruited to the study shortly after birth. The population was defined as residents of Gateshead delivering a baby between June 1999 and May 2000.

Data were collected from three sources: the family, NHS staff and a special health check. The family completed questionnaires at birth, 6 weeks, 4, 8 and 12 months and at each time point their baby's weights were transcribed from their Parent Held Child Record for the study. Over the year, the questionnaires covered the child's feeding and food preferences, illnesses, behaviour and temperament, as well as the mother's eating patterns and the family's life events. A follow-up study collected similar data at 2½ years, and further study of the cohort is planned.

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**Principal Investigators**: Dr Elizabeth Towner; Dr Charlotte Wright

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**Collaborator(s)**: Dr RF Drewett (Durham)

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**Project Staff**: Dr Kathryn Parkinson

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**Funding**: NHS Executive Northern and Yorkshire

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**Start and End dates**: 1 October 2001 – 31 March 2003

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**Publications associated with the Project**:

Parkinson KN, Wright CM, Drewett RF. Mealtime energy intake and feeding behaviour in children who fail to thrive: a population-based case-control study. *Journal of Child Psychology and Psychiatry*. 2004; **45(5)**: 1020-1035

# Lifecourse Epidemiology

# The Newcastle Thousand Families Study

**Abstract**:

The Thousand Families Study began in 1947 when all 1142 children born to mothers resident within the city of Newcastle upon Tyne in May and June of that year were recruited into a longitudinal cohort study. The study was originally designed to investigate risk factors for death from infection in infancy. However, the study evolved to become a detailed study of health in childhood summarised in three books. These children were followed in great detail until the age 15, by which time a vast amount of information had been prospectively recorded regarding their health, growth, education and socio-economic and family circumstances.

The follow-up of study members at age 50 lead by Professor Sir Alan Craft, Professor Sir George Alberti and Professor Louise Parker, was prompted by a change in the focus of chronic disease epidemiology to investigate the role of fetal growth, socio-economic circumstances and experience and behaviour throughout life. Regaining contact with study members and adding detailed information on their health and lifestyle during adulthood to the existing information from earlier in life provided a unique opportunity to investigate lifecourse determinants of disease in middle age. The new study aimed to assess the relative contributions to health at age 50 of factors operating at different stages of an individuals life. From this we can relate factors at birth, in infancy and in childhood to a number of adult health outcomes. The remainder of this section details progress, including publications and funding, since the beginning of 2002. Information on publications prior to this date is available on the Thousand Families Study website: http://www.ncl.ac.uk/plerg/Research/1000F/1000history.htm

**Cardiovascular disease and the central metabolic syndrome**

The raising of the hypothesis that poor fetal growth increases the risk of cardiovascular disease and central metabolic syndrome was a key reason for resurrecting the Thousand Families Cohort study in the mid 1990's. Central metabolic syndrome (CMS) is the 'clustering' of certain cardiovascular disease risk factors and is associated with an increased risk of both diabetes and cardiovascular disease. The risk factors included within this 'cluster' include obesity, high blood pressure and insulin resistance. In this cohort we showed an effect of childhood catch-up growth on CMS risk at age 50 in men, but that for both men and women the most important factors in preventing CMS appear to be a healthy adult lifestyle.

The results of an investigation of the lifecourse predictors on insulin resistance and sensitivity were presented at the European Diabetes Epidemiology Group (EDEG) meeting in Salerno, April 2004, and at the plenary session of the 3rd Annual Conference on Epidemiological Longitudinal Studies (CELSE) in Bristol, September 2004 (both by Dr Mark Pearce). Again the results suggest a limited effect of early life on future health in middle age. The results of a study investigating whether fetal influences on CMS risk may be mediated through adult body composition was also presented at EDEG meeting in Salerno, April 2004 by Dr Nigel Unwin. A further abstract was presented at the EDEG meeting by Louise Hayes, this time concentrating on which factors throughout life predict the absence of metabolic syndrome in overweight study members.

Parental diabetes was reported in the self-completion questionnaires at age 50. A subsequent paper reported no association between the birth weight of study members and whether their parents had ever been diagnosed with diabetes. Ongoing work is investigating lifecourse influences on individual components of the central metabolic syndrome and other markers for cardiovascular disease.

### *Helicobacter pylori*

Cohort members were assessed for *Helicobacter pylori* seropositivity at age 50 using an ELISA method. The data generated were used as control data in two published studies; one comparing IgG subclass responses in 4 populations (Thousand Families Study members, an adult Gambian population and 2 paediatric populations, one from the UK and one from the Gambia), the second investigating IgG subclass responses in relation to duodenal ulcers. Results suggesting a protective effect of breast feeding on *Helicobacter pylori* infection in men of this study were presented at CELSE in Bristol in September 2004 by Dr Campbell. *Helicobacter pylori* has also been investigated with respect to tooth loss, suggesting that the proposed relationship between the two outcomes may be simply due to confounding by social class.

### Oral Health

The oral health component of the study has been a collaboration with Professors Jimmy Steele and Angus Walls from the School of Dental Sciences and Ms Justine Mason who successfully obtained a B.Med.Sci. degree with a thesis on the lifecourse determinants of oral health and oral health-related quality of life in the cohort. The first paper to appear from this collaboration presented the results of the investigation into lifecourse determinants of tooth retention at the age of 50 years and received worldwide media attention. Little effect of early life was shown, with the major factor in tooth retention being adult socio-economic position and lifestyle (in particular cigarette smoking). Results suggesting an effect of early disadvantage on oral health related quality of life in men, but not for women, for whom the number of retained teeth is the most important factor, were was presented at the annual British Dental Research Conference in 2004. Justine Mason was awarded the prize for best student presentation and was nominated to present her findings at the International Dental Research Conference in Baltimore in March 2005.

### Social Inequalities and Adult Health

A paper, resulting from work led by Dr Martin White and Dr Jean Adams, reported on the tracking of socio-economic indicators and the subsequent influence of socio-economic mobility on adult health. Socio-economic position at different stages of life was associated with self-reported limiting long-standing illness in men, but no such associations were seen for women.

### Parenchymal Breast Tissue Density

Previous research has suggested that fetal and childhood growth may influence breast tissue density. We have been awarded £5,956 by the Newcastle Healthcare Charity to carry out an investigation of lifecourse predictors of parenchymal breast tissue density, which is commonly used as a marker for risk of breast cancer. This will involve sending questionnaires on lifetime oestrogen exposure to all women in the study and asking for access to their mammography films. This component is due to begin in Spring 2005

### Growth and Obesity

The effect of deprivation on growth in the cohort was compared with that in a more recent birth cohort. No evidence of a changing influence of socio-economic deprivation on growth in childhood was found, despite increases in mean height over a 40-year period.

### Other ongoing work

Other areas of work completed during the period covered by this report include investigations of the lifecourse influences on bone mineral density and skeletal size, the validity of self-reported smoking, the validity of self-reported height loss and the first results of a programme of work

developed with Professor Ian Deary (University of Edinburgh) looking at the relationship between childhood IQ and factors (both health and lifestyle) in later life.

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**Principal Investigators**: Professor Louise Parker; Dr Mark Pearce (Director of the Study since February 2003)

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**Thousand Families Steering Group**: Professor Louise Parker (Chair); Professor Sir George Alberti; Professor Sir Alan Craft; Dr Mark Pearce; Mrs Jean Taylor (Study Member); Dr Nigel Unwin

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**Collaborator(s)**: Dr Jean Adams; Dr Ashley Adamson; Professor Sir George Alberti; Dr Fraser Birrell; Mrs Mwenza Blell (University of Durham); Dr David Campbell; Dr Martin Charlton (National University of Ireland); Dr David Chinn; Professor Sir Alan Craft; Professor Ian Deary (University of Edinburgh); Professor Nicol Ferrier; Dr Roger Francis; Professor John Gibson; Mrs Louise Hayes; Dr Fu-Meng Khaw; Professor Anne Le Couteur; Ms Justine Mason; Professor John Mathers; Dr Elizabeth McIntyre; Dr Lesley McLean; Professor John O'Brien; Dr Tanja Pless-Mulloli; Dr Tessa Pollard (University of Durham); Dr David Rawlings; Dr Adrian Rees; Dr Caroline Relton; Dr Beverly Shipley (University of Edinburgh); Professor Jimmy Steele; Dr Julian Thomas; Dr Paul Tiffin; Dr Stephen Tuck; Dr Nigel Unwin; Professor Thomas von Zglinicki; Professor Mark Walker; Professor Angus Walls; Dr Mark Welfare; Dr Martin White; Dr Charlotte Wright (PEACH Unit, Glasgow); Professor Allan Young

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**Funding**: Various sponsors have contributed to the survey including The Wellcome Trust, The Knott Trust, The Minnie Henderson Trust, The Special Trustees of the Newcastle Hospitals Trust

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**Start and End Dates**: Ongoing since 1947

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**Publications associated with the Project**: (2002-2004):

Adams J, White M, Pearce MS, Parker L. Lifecourse measures of socio-economic status and self-reported health at age 50: Prospective cohort study. *Journal of Epidemiology and Community Health.* 2004; **58**: 1028-1029

Campbell DI, Pearce MS, Thomas JE. IgG subclass responses in childhood *Helicobacter pylori* duodenal ulcer: evidence of T-helper cell type 2 responses. *Helicobacter.* 2004; **9**: 289-292

Campbell DI, Sullivan PB, Pearce MS, Dale A, Parker L, Thomas JE. IgG subclass responses to Helicobacter pylori vary with age in populations with different risk of gastric carcinoma. *Clinical and Diagnostic Laboratory Immunology.* 2004; **11**: 631-633

Craft AW. Fetal programming or adult lifestyle. Lessons from the Newcastle 1000 Families Study. *Hong Kong Journal of Paediatrics.* 2003; **8**: 346-353

Parker L, Lamont DW, Unwin N, Pearce MS, Bennett SMA, Dickinson HO, White M, Mathers JC, Alberti KGMM, Craft AW. A lifecourse study of risk for hyperinsulinaemia, dyslipidaemia and obesity (the central metabolic syndrome) at age 49-51. *Diabetic Medicine* 2003; **20**: 406-415

Pearce MS, Steele JG, Mason J, Walls AWG, Parker L. Do circumstances in early life contribute to oral health in middle age? *Journal of Dental Research* 2004; 83: 562-566

Wright CM, Parker L. Forty years on: The effect of deprivation on growth in two Newcastle birth cohorts. *International Journal of Epidemiology* 2004; **33**: 147-152

# The Impact of Place of Birth on Insulin Resistance and Reproductive Function in Premenopausal Pakistani and European Origin Women

**Abstract**:

The overall purpose of this study is to investigate the effect of early environment on insulin resistance and reproductive function by comparing immigrants from Pakistan with Pakistani and European origin women born in the UK. The study is based partly on Yajnik's proposition that the fact that babies born in South Asia have a greater proportion of body fat helps explain their propensity to develop insulin resistance in affluent environments. We also aim to test the hypothesis that girls who grow more slowly in early life have reduced ovarian function as adults.

The aims are to test the following predictions:

1. Women born in Pakistan will have a greater proportion of body fat and higher levels of central body fat than women born in the UK.
2. Women born in Pakistan will show more evidence of insulin resistance than women born in the UK.
3. Women born in Pakistan will have lower levels of sex hormones binding-globulin and higher levels of androgens than women born in the UK.
4. Women born in Pakistan will have lower levels of oestradiol and progesterone than women born in the UK.

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**Principal Investigators**: Dr Nigel Unwin; Dr Tessa Pollard (University of Durham)

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**Collaborator(s)**: Dr Colin Fischbacher (ISD, Edinburgh)

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**Project Staff**: Jazz Chamley

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**Funding**: Newcastle Healthcare Charity

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**Start and End dates**: 1 May 2002 – 31 October 2004

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**Publications associated with the Project**:

Pollard TM, Unwin N, Fischbacher C, Chamley J. Features of metabolic syndrome in premenopausal women in the UK: immigrants from Pakistan compared to Pakistani and European-origin women born in the UK. American Association of Physical Anthropologists Annual Meeting, Milwaukee, April 2005.

Pollard TM, Unwin N, Fischbacher C, Chamley J. Reproductive function in women of South Asian origin in the UK: a biocultural perspective. Human Biology Association Annual Meeting, Milwaukee, April 2005.

# The Biological Pathways Linking Socio-Economic Status and Health: Socio-Economic Status, Health and Ageing

**Abstract**:

*Objectives*: To conduct a comprehensive review of existing explanations of socio-economic health differences (SEHD). To develop a model of the possible biological pathways linking socio-economic status (SES) and health. To test one part of this model (as described here).

*Background*: Previous work has failed to establish the fundamental, biological mechanisms linking SES and health. Ageing is a universal phenomenon and some indirect markers of biological ageing have been consistently reported to be socio-economically distributed, including: age of death, age of onset of limiting disability and healthy life expectancy. Biological ageing is due to the accumulation of cellular damage and the rate of biological ageing is influenced by both environmental and genetic factors. We propose that the mechanisms underlying biological ageing are central to health and that the influence of socio-economically distributed environmental factors on the rate of damage accumulation is one fundamental, biological mechanism linking SES and health.

*Null hypothesis*: Markers of biological ageing are not socio-economically distributed.

Study 1 - Cross sectional investigation of socio-economic distribution of telomere length in middle-aged people. Telomere length is thought to be a accurate biomarker of cellular damage. Pilot work has confirmed that a relationship between household income and telomere length and a full scale study is now under way.

Study 2 - Retrospective cohort study of socio-economic distribution of age of development of first colon cancer in people with hereditary non-polyposis colon cancer (HNPCC). HCPCC is a DNA repair disorder leading to an accelerated rate of cellular damage accumulation. Development of colon cancer in individuals with HNPCC is an indirect marker of cellular damage accumulation and, therefore, biological ageing. The results of this work were disappointing due to a number of biases in the data set used but have been submitted for publication nevertheless.

Study 3 - Analysis of 10 years of data from the local cancer registry to determine the relationship, if any, between age of diagnosis of cancer and socio-economic status in those with breast, prostate, colorectal and lung cancer. Two methodological studies of the most appropriate way to measure SES are also being performed.

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**Principal Investigators**: Dr Martin White

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**Collaborator(s)**: Dr Nigel Unwin; Professor Louise Parker; Professor Thomas von Zglinicki; Professor John Burn; Professor John Mathers

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**Project Staff**: Dr Jean Adams

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**Funding**: Faculty of Public Health Medicine and BUPA

**Start and End dates**: 17 September 2001 – 16 September 2004

**Publications associated with Project**:

Adams J, Audisio RA, White M, Forman D. Age-related variations in progression of cancer at diagnosis and completeness of cancer registry data. *Surgical Oncology*. 2004; **13**: 175-179

Adams J, White M, Pearce MS, Parker L. Lifecourse measures of socio-economic position and self-reported health at age 50: prospective cohort study. *Journal of Epidemiology and Community Health*. 2004; **58**: 1028-1029

Adams J, White M. Biological ageing: a fundamental link between socio-economic status and health? *European Journal of Public Health.* 2004; **14**: 331-334

Adams J, White M, Forman D. Are there socio-economic gradients in stage and grade of breast cancer at diagnosis? A cross sectional analysis of UK cancer registry data. *British Medical Journal*. 2004; **329**: 142-3

# Stroke Incidence Study for the Hai District and Dar-es-Salaam, Tanzania

**Abstract**:

All incident stroke cases in two of the Adult Mortality and Morbidity Project (AMMP) study areas. (Hai, a relatively prosperous rural area (N = 150,000) and a geographically defined urban population area of Dar-es-Salaam (N = 70,000)), are being collected from June 2003 to June 2006. Incident stroke cases are identified by enumerators and key informants in the AMMP team. Consenting cases are transported to hospital for investigations including CT head scan, echocardiogram, ECG, blood tests and DNA. Cases are followed up at 1 month and 6 months to assess outcome in terms of morbidity and fatality. Two age and sex matched controls recruited for each person with stroke from the AMMP database undergo the same investigations as the stroke patients apart from echocardiogram (unless atrial fibrillation) and CT head scan. The project pays for all costs of transport, hospital admission, investigations and treatment for any long-term conditions identified, such as hypertension.

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**Principal Investigators**: Dr Richard Walker

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**Co-investigators**: Dr Nigel Unwin; Dr Mark Swai; Dr Ferdinand Mugusi; Professor Sir George Alberti

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**Collaborator(s)**: Professor Cam Donaldson and Dr Phil Shackley (Health Economics)
Professor Patrick Chinnery – Genetics; Gerry Mshana – Anthropology, Dar-es-Salaam

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**Project Staff**: No salaried project staff in the UK.

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**Funding**: Wellcome Trust

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**Start and End dates**: January 2003 – June 2006

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**Publications associated with Project**:

Tanzanian Stroke Incidence Project - First year data for the Hai district. Poster presentation. *British Association of Stroke Physicians*. January 2004

# Palliative Care in Parkinson's Disease

**Abstract**:

All patients with idiopathic Parkinson's disease, according to the UK Brain Bank Criteria, known to the North Tyneside Parkinson's disease service were approached. Those who consented to take part in the study underwent in-depth interview with research doctor who has a palliative care background. Comparative scales were completed in relation to disease staging, impairment, quality of life, pain and symptom load.

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**Principal Investigators**: Dr Richard Walker; Dr Wendy Prentice; Dr Mark Lee

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**Collaborator(s)**: Dr Tony Hildreth (University of Sunderland)

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**Project Staff**: Dr Mark Lee

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**Funding**: Northumbria Healthcare NHS Trust

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**Start and End dates**: November 2003 – November 2005

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**Publications associated with Project**:

Lee M, Walker RW, Prentice W. The role of palliative care in Parkinson's disease. *Geriatric Medicine*. April 2004; 51-54

Lee MA, Prentice WM, Walker RW. A Palliative Care Assessment of Pain in Parkinson's Disease. *British Pain Society Annual Meeting in Edinburgh* (8th-11th March 2005). (Poster presentation accepted)

# Action on Non-Communicable Diseases in Sub-Saharan Africa

**Abstract**:

**Objectives**:
To develop, implement and evaluate sustainable models for improving the detection and management of common non-communicable diseases (NCDs) (diabetes, hypertension, asthma and epilepsy) in primary health care in sub-Saharan Africa.

**Study design**:
There are four main phases to the study:

Phase 1 - Documentation of the structure and functioning of the health care systems in the project sites (2 sites in Cameroon, 2 in Tanzania), assessment of the quality of primary health care for NCDs in the project sites and investigation of health beliefs and perceptions of NCDs, using rapid assessment methods

Phase 2 - Development of intervention packages in consultation with health care planners, workers and patients

Phase 3 - Implementation and evaluation of intervention packages

Phase 4 - Writing up and dissemination of the project findings

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**Principal Investigators**: Dr Nigel Unwin

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**Collaborator(s)**: Dr Ferdinand Mugusi, Consultant Physician, Muhimbili University, Dar Es Salaam Tanzania; Dr Jean-Claude Mbanya, Consultant Physician, University of Yaounde, Cameroon; Dr Beverley Balkau, Director of Research, INSERM, Paris; Professor Sir George Alberti

Other Newcastle collaborators are Dr Richard Edwards, Dr Colin Fischbacher, Dr Tanja Pless-Mulloli, Dr Sushma Acquilla, Dr David Parkin, Dr Philip Setel, Dr Martin White, Dr David Whiting

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**Project Staff**: Louise Hayes

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**Funding**: European Commission

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**Start and End dates**: 1 March 1999 – 28 February 2003

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# The Prevalence of Parkinson's Disease in North Tyneside and North Northumberland: a Population-Based Study of Epidemiology, Service Use and Anticipated Care Need

**Abstract**:

These are case finding studies conducted on a geographically defined urban population (N = 110,000) of North Tyneside and a geographically defined rural population in north Northumberland (N = 70,000). Case finding methods include Northumbria Parkinson's disease service database, neurology outpatient lists, GP lists (diagnostic category and Parkinson's disease (PD) drugs) and secondary care pharmacy records. Idiopathic Parkinson's disease is diagnosed according to the UK Brain Bank Criteria. In those who consent, a detailed questionnaire and examination are carried out in their own home environment.

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**Principal Investigators**: Dr Robert Porter

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**Collaborator(s)**: Dr Nigel Unwin

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**Project Staff**: Dr Bob Porter

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**Funding**: Northumbria Healthcare NHS Trust

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**Start and End dates**: November 2001 – February 2004

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**Publications associated with Project**:

The prevalence and nature of Parkinson's disease in an area of North Tyneside: a study looking at disease severity and frequency of Disease related complications. Dr R Porter. MD Thesis – accepted December 2004.

Porter R, Walker R. The Prevalence of Idiopathic Parkinson's disease in an area of North Tyneside in the North East of England. *International Movement Disorder Conference*, Rome, June 2004 (poster)

Porter R, Walker R. The problem of calculating the prevalence rate of Parkinson's disease. BGS Northern Regional meeting, 22.3.02 – platform

# Pilot Study: Long-Term Sequelae of Radiation Exposure from Computed Tomography Scans on Children

**Abstract**:

A retrospective controlled follow-up study of 100,000 children exposed to computed tomography (CT) scanning under the age of 15 study (and 100,000 non-exposed children) is planned to investigate the potential long-term sequelae of radiation exposure from CT scanning of children, as practiced in the United Kingdom since 1982. The planned study will be part of an international collaboration which at the present time includes groups in the UK, Sweden, France and the United States (with other countries to be added) and will be the first comprehensive assessment of the long-term effects of CT scanning of children. Before this study can take place, a detailed pilot study is required.

The main objective of this pilot study is to test planned methodologies (in terms of identifying exposed individuals, collecting adequate dosimetric and confounding information and developing data abstraction forms to be used in the full study) and where appropriate to adjust plans for a national study. Data collection methods are being developed and tested using radiology records from within the Newcastle upon Tyne hospitals. The results of this pilot study will contribute to the planning and execution of the national study, which will be the largest study within the proposed international collaboration.

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**Principal Investigators**: Dr Mark Pearce

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**Collaborator(s)**: Professor Louise Parker; Radiology Departments within the Newcastle NHS Trust; Dr Kieran McHugh (Great Ormond Street, London); Scientists at the Radiology Branch of the National Cancer Institute, USA; the Karolinska Institute, Sweden.

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**Project Staff**: Dr Mark Pearce

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**Funding**: National Institutes for Health, USA for a pilot study.

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**Start and End dates**: 1 November 2004 – 31 May 2005

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# PLERG Research Grants 2002-2004

(Full or partial income to PLERG)

| Project | Total Funding |
|---|---|
| SPARCLE (Commission of the European Community) | £850,000 |
| Northern Congenital Abnormality Survey (Department of Health) | £382,263 |
| Stroke incidence study for Hai District (the Wellcome Trust) | £337,040 |
| NECCR Core funding 2004-05 (NECCR Fund) | £316,935 |
| Life Expectancy in cerebral palsy (Medical Research Council) | £300,000 |
| FOCUS: The development and dissemination of cost-effective training in systematic observation and assessment of human behaviour within English higher education psychology courses (Fund for the Development of Teaching and Learning) | £249,942 |
| PAMPER (The Wellcome Trust) | £238,221 |
| Action of NCDs in Sub-Saharan Africa | £217,355 |
| FACTS (National Lotteries Board) | £211,535 |
| Child Health Info (Tyne and Wear Action Zone) | £194,673 |
| Evaluation of Child Pedestrian (Department for Transport, local govt) | £169,590 |
| Baby Express (Family Support Unit (Home Office)) | £150,000 |
| Feasibility Study (Department of Health) | £148,730 |
| School-Based Group Therapy for Children at Risk of Mental Disorders (NHS Chief Executive) | £130,000 |
| CGD Registry (Chronic Granulomatous Disorder Research Trust) | £117,568 |
| Dealing with Disadvantage (University College London) | £105,000 |
| Autistic Spectrum Disorder (The Northern Rock Foundation etc.) | £101,324 |
| North Cumbria Community Genetics Project (Westlakes Research Institute, Cumbria) | £100,000 |
| Autistic Spectrum (The Health Foundation) | £96,216 |
| Community Acquired Pneumonia (The Sir Halley Stewart Trust; Children's Research Fund) | £73,651 |
| Prevalence of Parkinson's Disease (Northumbria Healthcare Trust) | £73,000 |
| Cancer Epidemiology (NECCR) | £62,350 |
| Quality of Life and Childhood Disability (ESRC) | £46,813 |
| Perinatal Mortality in the N. Region (Newcastle Special Trustees) | £45,499 |
| FPH/BUPA Fellowship (Faculty of Public Health of the Royal College of Physicians) | £42,500 |
| Vulnerable Road Users (Department for Transport) | £37,500 |

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|---|---|
| Toddler Feeding (Department of Health) | £32,597 |
| Childhood Injury (Children's Foundation) | £31,948 |
| Wellbeing for Autism Index (3N's Trust) | £30,000 |
| Breath Analysis (Children's Foundation) | £20,000 |
| Scoping for Public Health Observatory (N & Y Public Health Observatory) | £19,800 |
| Kerbcraft Road Safety (Department of Transport) | £19,784 |
| Systematic Review of Parent-Implemented Early Intervention for Children with ASD (Nuffield Foundation) | £18,350 |
| Cerebral Palsy (Newcastle Healthcare Trust) | £16,249 |
| Langerhans Cell Histiocytosis Research (The Histiocytosis Research Trust) | £15,000 |
| Baby Express (Garfield Weston Foundation) | £15,000 |
| Long-term effects of CT Scans on Children (NIH, USA) | £13,569 |
| Will it Ever Stop? (Inge Wakehurst Trust) | £11,519 |
| Models of Paediatric Services (The NHS Confederation & RCPCH) | £10,000 |
| Injury to Children (Health Development Agency) | £10,000 |
| Baby Express video study (Sutton Trust) | £10,000 |
| International Molecular Genetic Study of Autism (European Consortium) | £9,833 |
| Register of Cryptorchidism (Birth Defects) | £9,605 |
| Readmission to Hospital (Newcastle Healthcare Charity) | £9,150 |
| Life Skills Initiative (Tyne and Wear Health) | £7,942 |
| Survey of Child Road Safety (University of Surrey) (total grant £38,783 – Newcastle portion £6,840) | £6,840 |
| Lifecourse Predictors of Breast Tissue Density [forms part of Thousand Families Study] (Newcastle Healthcare Charity) | £5,956 |
| WHOOPS (The Children's Foundation) | £4,840 |
| Measuring Fun in Parent-Child Interaction (Newcastle University Hospital Special Trustees) | £4,595 |
| Laser Schemes (Royal Society for the Prevention of Accidents) | £3,960 |
| Serum IgG subclass (Newcastle Health Care) | £2,062 |
| Baby Express (Newcastle Education Action Zone) | £2,000 |
| Health Evidence Network (World Health Organisation) | £1,733 |
| **TOTAL FUNDING** | **£5,140,037** |

# Publications

Members of PLERG highlighted

## 2004 publications

1. A-Rahman A, **Spencer D**. Totally implantable vascular access devices for cystic fibrosis (Cochrane Review update). In: The Cochrane Library. Issue 3, 2004, Chichester, UK: John Wiley & Sons, Ltd

2. **Adams J,** Audisio RA, **White M**, Forman D. Age-related variations in progression of cancer at diagnosis and completeness of cancer registry data. *Surgical Oncology*. 2004; **13(4):** 175-179

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