

A Guide to Organisations Critical of Human Genetics and Embryology

May 2003



ProgressEducationalTrust

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This guidebook is intended as a source of information for anyone who wants to assess the claims of organisations operating in the field of human genetics and embryology. The focus is on those pressure groups which actively campaign against new developments or technologies.

The guide is largely factual, but with comments added for each organisation.

The authors have attempted to ensure the accuracy of the information provided. Most (but not all) of the text has been sent to the respective organisations to check - some of which did not respond. However, the information is provided for guidance only.

Association of Medical Research Charities

The Association of Medical Research Charities (AMRC) has over 100 member charities who together contribute over £500 million to medical research every year in the UK. They are a major source of funding for research in all areas of medicine in the UK. The AMRC works to advance medical research in the UK. Its activities focus on improving the effectiveness of the charitable sector in medical research.

Genetic Interest Group

The Genetic Interest Group (GIG) is a national alliance of organisations with a membership of over 120 charities which support children, families and individuals affected by genetic disorders/genetic diseases. Its primary goal is to promote awareness and understanding of genetic disorders so that high quality services for people affected by genetic conditions are developed and made available to all who need them.

Progress Educational Trust

Progress Educational Trust (PET) is a national charity set up to enhance the public understanding of and engagement with genetic and reproductive science. It aims to achieve this by publishing news and information on key developments; holding conferences and debates on social, legal and ethical issues; developing educational materials for schools and universities and seeking to influence public opinion and public policy.

May 2003

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Human Genetics Alert

Address Unit 112 Aberdeen House, 22-24 Highbury Grove, London N5 2EA
Telephone 020 7704 6100
Website www.hgalert.org

Founded 1999
Membership Described as a small group less than a thousand.
Leading figures David King
Scientific advisory panel None
Annual report None
Annual budget £50,000 approximately
Sources of income Substantial income from the Joseph Rowntree Foundation.

Describes itself as: 'an independent watchdog group based in London. We are not opposed to genetic research. However, we are opposed to some developments, such as genetic discrimination, cloning and inheritable ('germ line') genetic engineering of human beings.'

HGA is developing a range of campaigning approaches. In addition to traditional lobbying around legislation (e.g. on cloning and genetic discrimination), HGA is working on proactive projects which aim to give people greater control over important personal decisions which involve genetics.'

HGA acknowledges that it is 'widely expected that these changes will bring major health benefits' but believes that 'the human genetics revolution also raises profound social and ethical problems, including a possible resurgence of eugenics [and that there is] a widespread concern that genetics is running far ahead of society's ability to cope with these issues.'

Activities: produces the useful Human Genetics Alert e-mail bulletins with a wide variety of news (many of the items are reported from journals or newspapers). Occasionally HGA adds its own commentary or editorial comment. HGA also produces regular printed newsletters and briefings, which can be downloaded from their website. HGA is working to get the issues on the agendas of other organisations and, for example, organises meetings to do that.

Comments: Human Genetics Alert describes itself as 'sceptical'. It does not oppose genetics research completely, but is critical of many developments, and wants greater '*democratic control of human genetics*'. In particular, HGA is concerned about how genetics knowledge is used, controlled and commercialised.

HGA represents the radical and vocal minority. It certainly has a voice in the debate, and may have contributed to decisions like the insurance industry moratorium on the use of genetic testing. In reality though, groups such as HGA and others only gained influence in that debate because bigger organisations like the Human Genetics Commission were involved. Overall HGA is probably too small and remote from the mainstream to have much influence.

GeneWatch UK

<i>Address</i>	The Mill House, Manchester Road, Tideswell, Buxton, Derbyshire SK17 8LN
<i>Telephone</i>	01298 871898
<i>Email</i>	mail@genewatch.org
<i>Website</i>	www.genewatch.org
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<i>Founded</i>	January 1998
<i>Membership</i>	No formal membership. Subscribers receive briefings.
<i>Leading figures</i>	Dr Sue Mayer, Executive Director
<i>Management</i>	Board of six directors
<i>Scientific advisory panel</i>	None
<i>Annual report</i>	Accounts submitted to Companies House
<i>Annual budget</i>	Approximately £110,000
<i>Sources of income</i>	Approximately: 70-75% from charitable trusts, 20% from commissioning, 5-10% from subscriptions and donations.

Describes itself as: 'an independent, voluntary, not-for-profit organisation. Our aims are to ensure that genetic technologies are developed and used in the public interest and in a way which promotes human health, protects the environment and respects human rights and the interests of animals. GeneWatch works to promote environmental, ethical, social, human health and animal welfare considerations in decision-making about genetic engineering and other genetic technologies. GeneWatch is not opposed to genetic technologies in principle but believes that public participation is crucial for robust and effective decision-making and that this can only take place in the context of openness, where debate is well informed and proper weight is attached to public concerns and aspirations for the future.'

Activities: GeneWatch conducts research and analysis, and campaigns and provides information on many aspects of genetics. It has produced a series of briefings; conducted research and analysis; investigated new approaches to decision-making; published articles and participated in radio and television debates; given talks to a variety of groups; advised and attended meetings with regulators, Government Ministers, Members of Parliament and scientists and developed a comprehensive website.

Comments: GeneWatch is adept at media work, lobbying and networking. It has influence, but lacks the resources for sustained campaigning in the same way as some larger anti-vivisection or pro-life groups. Its radical views exclude it from some debates. For example, opposing all gene patents on a philosophical basis precludes GeneWatch from usefully discussing how patent criteria can best be applied.

Like many pressure groups, GeneWatch carefully selects the examples and evidence which suit its pre-conceived viewpoint. In its recent report on GM animals, GeneWatch took advice mostly from organisations already opposed to animal use, rather than from the research community. There is no scientific committee and no obvious mechanism for peer review or independent scrutiny to achieve the 'public interest' it claims. It appears more that GeneWatch represents the narrow agenda of those who share its views.

Consumers' Association

<i>Address</i>	2 Marylebone Road, London NW1 4DF
<i>Telephone</i>	020 7770 7000
<i>Website</i>	www.which.net/campaigns/health/genetics/index.html

<i>Membership</i>	Over 900,000 members and 700,000 subscribers
<i>Leading figures</i>	N/A
<i>Annual budget</i>	£50.7m expenditure in 2002, 15% of which was spent on campaigning. Note: The Consumers' Association is a charity; <i>Which?</i> is a limited company.
<i>Sources of income</i>	From sales of its <i>Which?</i> range of magazines and books

Describes itself as: 'an independent, not-for-profit consumer organisation. It is the largest consumer organisation in Europe. Entirely independent of government and industry. CA campaigns on a wide range of issues of importance to consumers, one of which is health. The aim of CA's health campaign is to ensure that the public has better access to and information about health care; greater levels of empowerment, including informed consent and confidentiality; effective redress; and assured safety for consumers of existing and emerging health services, products and technologies. These objectives are supported through health policy research and reports published in consumer magazines *Which?* and *Health Which?*. CA has had a long-standing interest in general issues related to patient consent and confidentiality of patient information, and is very interested in the development of specific policy related to the storage and use of personal genetic information.'

Activities: CA carries out quantitative and qualitative research to base its campaigns on. It also gets feedback from subscribers to *Which?* and its own database of complaints. It carried out a range of activities on genetics including: qualitative and quantitative research, consultation responses, media work and press releases, briefings, parliamentary lobbying and information sheets. The CA has also hosted discussions on a other issues relating to genetics research in a magazine *Consumer Policy Review*.

Comments: The Consumers' Association (CA) has a well known role, namely to represent the consumer perspective. It has established a credible reputation for commenting on health issues, for example, through the well regarded *Drugs and Therapeutics Bulletin*.

When it comes to genetics the CA claims to criticise only where it identifies a genuine potential for harm to individuals (what it calls 'consumer detriment'). Their main areas of concern are misinformation about genetics and genetic testing, and the potential for subsequent discrimination, e.g. in insurance or employment. CA claims it wants to get its approach to genetics policy 'right', and has been willing to pass documents to a range of organisations for comment before publication. The CA does make statements recognising the health benefits of genetics. But it has tended to fall into a campaigning role with most of its emphasis on the problematic aspects of genetics. The CA has collaborated with GeneWatch to the extent that there are concerns that it is also exaggerating the problems. Whilst its articles in *Health Which?* have provided useful information, CA appears to want to represent the 'worried' consumer rather than those who wish to see the benefits come sooner.

British Council of Disabled People

<i>Address</i>	Litchurch Plaza, Litchurch Lane, Derby DE24 8AA
<i>Telephone</i>	01332 295551
<i>Email</i>	general@bcodp.org.uk
<i>Website</i>	www.bcodp.org.uk
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<i>Founded</i>	1981
<i>Membership</i>	133 groups in full membership, the majority of whose members and executives must have a disability. Disabled people can join as individuals and other organisations can affiliate, but only the groups set policy
<i>Leading figures</i>	On genetics issues: Bill Albert (Chair of BCODP's International Sub Committee and author/coordinator of the BCODP's work on genetics)
<i>Scientific advisory panel</i>	None
<i>Accountability</i>	Consults groups and individuals in membership
<i>Annual budget</i>	£655 000
<i>Annual report</i>	'Fighting Talk' (2001/02)
<i>Sources of income</i>	Community Fund and Project Grants
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Describes itself as: 'BCODP is the *only* national umbrella organisation to be democratically set up by disabled people themselves to represent their interests at the national level. We are seen as the disabled people's movement in Britain and we are recognised by the United Nations through our membership of the world disabled people's movement; Disabled People's International (DPI). BCODP is extremely proactive as the national representative body for organisations controlled by disabled people. Through the promotion of the social model of disability, BCODP has had a profound effect on the thinking on disability issues in the UK. We are active on a wide range of issues affecting disabled people.'

Activities: In 1997 BCODP organised a seminar on Bioethics and Disabled People, with support from The Wellcome Trust and the Joseph Rowntree Foundation. BCODP's National Council subsequently approved *The New Genetics and Disabled People* (<http://www.bcodp.org.uk/about/genetics.shtml>) after a period of consultation and discussion. Around the same time, in February 2000, 130 disabled people and parents met in the UK to discuss bioethics and human rights. This was the first occasion of its kind, bringing together delegates from DPI organisations in twenty-seven countries across the world and developing similar themes to those in BCODP's own statement.

Bill Albert is a member of the Government's Human Genetics Commission. He is currently involved in a 'bioethics training project', which aims to forward DPI's work 'by giving disabled people throughout Europe the information they need to take part in national and international debates on bioethics'. However, genetics is far from being the main concern of the group as a whole. There is no mention of genetics in its most recent Annual Report; the year 2000 may have marked a relative highpoint in its interest in the subject, for the moment at least.

Comments: The BCODP's main aim is to influence decision-making, attitudes and policy, all of which it seeks to do through lobbying and argument. Its views might be described as the authentic radical end of the disability rights spectrum - highly critical, but tempered by an awareness of the futility of an outright rejectionist approach to genetic research: 'We are... not making a case against medical research, but rather one for a more equitable distribution of effort and resources in order that a real difference can be made now in the lives of disabled people.' It is not always easy for the group to agree an unambiguous position: *The New Genetics and Disabled People* takes the form of a consultation and many of the proposals are still provisional. Its long-term goals are radical and far-reaching. It has had some success over the past five and more years at the level of influencing media debate. But certainly in its own opinion, it has had less impact on substantial questions such as research directions and the philosophies that support those priorities.

Disability Awareness in Action

Address 11 Belgrave Road, London SW1V 1RB
Telephone 020 7834 0477
Email admin@daa.org.uk
Website www.daa.org.uk

Founded 1991
Leading figures On genetics issues: Rachel Hurst
Membership DAA is a collaborative project for four groups (see below)
Annual budget Approximately £100 000
Scientific advisory panel None
Accountability Consults groups and individuals in membership
Annual report Only a financial statement
Sources of income Numerous, including the Department of Health, The Foreign and Commonwealth Office and Comic Relief

Describes itself as: 'a collaborative project between: Disabled People's International; Impact; Inclusion International; World Federation of the Deaf. DAA was established to: provide a network for the exchange of information and experience between disabled people, and their representative organisations, world-wide; support disabled people's self-advocacy, and promote and protect disabled people's human rights.'

Activities: Rachel Hurst is a well-known disability rights commentator and campaigner on genetic issues. She argues: 'By ignoring the current understanding of disability as the interaction between a discriminatory and disadvantaging society and a person with impairments, the expenditure on cures far outweighs expenditure on services to support inclusion for disabled individuals. Above all, the threat of eugenic practices further isolates us and ignores the tremendous contribution that disabled people bring to society... Further advances and practices must be based on the furtherance of human rights, fundamental freedoms and human dignity, recognising, in particular, the potential rights of the unborn child who may exhibit the difference of disability.'

DAA has and continues to work closely with DPI Europe and its projects on genetics, rather than pursuing any independent projects of its own.

Comments: The DAA Human Rights Database was launched in 1999. It is, to their knowledge, 'the only systematic attempt to provide an international record of human rights violations against disabled people.' They are cautious of mainstream approaches to human rights and genetics, and critical of bioethics because they believe that contemporary notions of autonomy and individual rights allow what they consider to be eugenic choices to be made by individuals and society.

Disability Rights Commission

Address 222 Gray's Inn Road, London WC1X 8HL
Telephone 08457 622633
Email enquiry@drc-gb.org
Website www.drc-gb.org

Founded 25 April 2000
Membership The DRC is not a membership organisation
Leading figures On genetics issues: Agnes Fletcher & Caroline Gooding (staff)
Scientific advisory panel None
Accountability Governed by a large board of Commissioners, consults groups and individuals
Annual report Annual Review 2001-2
Annual budget Approximately £14 million
Sources of income Government grant

Describes itself as: 'an independent body set up by the Government to help secure civil rights for disabled people. Its statutory duties are:

- to work to eliminate discrimination against disabled people.
- to promote equal opportunities for disabled people.
- to encourage good practice in the treatment of disabled people.
- to advise the Government on the working of disability legislation (the Disability Discrimination Act (DDA) 1995 and the Disability Rights Commission Act 1999).'

Activities: The DRC has responded to major consultations on genetics and initiated discussion itself. Specifically, it has called for the Disability Discrimination Act to be extended to cover people with a predisposition to a genetic disorder, and produced a document *Genetics and Disability* (<http://www.drc-gb.org/drc/Documents/DRC%20genetics.pdf>).

After requests were made from LIFE, and to an extent from some disability rights campaigners, the DRC issued a somewhat opaque statement on termination of pregnancy on grounds of disability. It stated that 'Section 1(1)(d) is not inconsistent with the Disability Discrimination Act', but that it 'reinforces negative stereotypes of disability; and there is substantial support for the view that to permit terminations at any point during a pregnancy on the ground of risk of disability, while time limits apply to other grounds set out in the Abortion Act, is incompatible with valuing disability and non-disability equally.' The DRC promised to pursue the issue with the Secretary of State for Health, the medical professions and other relevant organisations.

Comments: The DRC is a relatively large organisation, and genetics is far from being its main focus. Indeed, currently it is fairly inactive on the issues highlighted above. Reflecting some of the more radical voices within the disability rights movement, the DRC's documents contain some fairly strong statements about, e.g., genetic testing and 'eugenics'. However, being a statutory body, the DRC, as an institution, takes a relatively mainstream approach to questions of choice and autonomy and advances a moderate position on concrete policy proposals.

The Royal Association for Disability and Rehabilitation (RADAR)

Address 12 City Forum, 250 City Road, London EC1V 8AF
Telephone 020 7250 3222
Email radar@radar.org.uk
Website www.radar.org.uk

Founded 1977
Membership >750 members, including individuals, organisations of and for disabled people, corporate and public sector organisations.
Leading figures No dedicated staff member covering genetic issues at present
Scientific advisory panel None
Annual budget £2,311,214 (2002)
Accountability Governed by a board of trustees, >50% of whom must be disabled
Sources of income Over half through their own activities. Indeed, a significant amount of money is spent on fundraising. The remainder is from a variety of sources, including a Government grant.
Campaigning manifesto 'The Seven Year Itch' (2003)

Describes itself as: 'RADAR's vision is of a society in which human difference is routinely anticipated, expertly accommodated and positively celebrated.' Its core business is 'campaigning for human rights for disabled people'.

Activities: In September 1999, RADAR published *Genes Are Us? Attitudes to Genetics and Disability*. This was the result of a survey of its 500 or so member groups, plus some other support groups for individuals and families with genetic conditions who are members of the Genetic Interest Group. The aim was 'to give a voice to disabled people and others whose lives are affected by impairment and disability on a subject almost universally recognised to be a major one for the next century'. Since then RADAR has gone through a difficult time financially, and has had to reduce the scale of its activities. Its current Campaigning Manifesto 'The Seven Year Itch' makes no mention of genetics, and the issue did not arise as a priority in the survey of RADAR's members that informed the document. Agnes Fletcher, coordinator of the *Genes Are Us?* project, now works at the Disability Rights Commission.

Comments: Although the survey results revealed a range of views, RADAR itself is fairly strongly committed to a critical and fearful position, informed by a disability rights perspective. Its current (relative) shortage of funds and priorities suggest however that it will not be active on the subject in the short to medium term.

Life

<i>Address</i>	Life House, Newbold Terrace, Leamington Spa, Warwickshire CV32 4EA
<i>Telephone</i>	01926 421587
<i>Website</i>	www.lifeuk.org

<i>Founded</i>	1970 (1977 as charity)
<i>Leading figures</i>	Jack Scarisbrick, Nuala Scarisbrick and Peter Garrett
<i>Membership</i>	37,000
<i>Annual budget</i>	£2,000,000

Describes itself as: 'a non-denominational registered charity whose members are committed to upholding the utmost respect for human life from fertilisation onward.' Its aims are to provide a nation-wide care service for pregnant women, unsupported mothers, women with problems relating to pregnancy, fertility or infertility, or suffering from the effects of abortion; to protect and preserve good health; and to educate the general public in all matters relating to pregnancy.'

Activities: Life's primary activity is services for pregnant women, with 134 pregnancy counselling centres in UK and Ireland. It also runs the Life Fertility programme in Liverpool and carries out work in schools.

Comments: Whilst Life concentrates primarily upon abortion issues, over the past few years assisted reproduction, cloning and genetics have become more important campaigning issues. Peter Garrett, Head of Education and Research, is Life's spokesman on these issues and is abreast of scientific developments, particularly in stem cell research. However, Life still relies on traditional methods of campaigning and lobbying and has not shaken off its religious image in the same way that CORE and ProLife Alliance have.

Society for the Protection of Unborn Children (SPUC)

<i>Address</i>	5-6 St Matthew Street, London SW1P 2JT
<i>Telephone</i>	020 7222 5845
<i>Website</i>	www.spuc.org.uk

<i>Founded</i>	1966
<i>Membership</i>	45,000
<i>Leading figures</i>	John Smeaton, National Director, Paul Tully, General Secretary
<i>Annual budget</i>	£1,600,000

Describes itself as: 'founded to uphold the principle of respect for human life, in particular the life of the unborn child. The society's constitution was, and remains, non-religious, endorsing the recognition by the world community in the 1959 United Nations

Declaration of the Rights of the Child that the child “needs special safeguards and care, including appropriate legal protection, before as well as after birth.”

Activities: SPUC’s main activity is parliamentary lobbying, primarily against abortion but also against IVF and related issues. It provides administrative support for the All-Party ProLife Group. SPUC has a charitable arm called the SPUC Educational Research Trust and publishes the *ProLife Times*.

Comments: SPUC’s primary focus is on abortion issues, but it has shown an increasing interest in assisted reproduction, cloning and genetics, as well as euthanasia, over the past few years. SPUC, which has a good parliamentary presence, was active around the passing of the Stem Cell Regulations in 2000/2001, publishing papers and briefing parliamentarians. However, it has failed to gain any real ground on these issues, partly because it lacks recognised individuals and is rather eclipsed by the activities of groups such as CORE and ProLife Alliance.

Comment on Reproductive Ethics (CORE)

<i>Address</i>	PO Box 4593, London SW3 6XE
<i>Telephone</i>	020 7351 1055
<i>Website</i>	www.coreethics.org

<i>Founded</i>	1994
<i>Membership</i>	No formal membership
<i>Leading figures</i>	Josephine Quintavalle, Founder
<i>Annual budget</i>	£25,000

Describes itself as: 'a public interest group focusing on ethical dilemmas surrounding human reproduction, particularly the new technologies of assisted conception... Absolute respect for the human embryo is a principal tenet. Of particular concern to CORE are matters relating to the physical and psychological welfare of children born from these various practices.'

Activities: CORE has organised two conferences in London and plans to have more. It carries out educational work at a tertiary plus level, through conferences, debates, written material, or the media. A focus of late has been parliamentary lobbying and bringing legal actions against the HFEA and other relevant organisations. Josephine Quintavalle is a member of ProLife Alliance, whose leader - Bruno Quintavalle - is her son.

Comments: CORE has a good media profile and Josephine Quintavalle is the most prominent member of the prolife lobby on issues surrounding assisted reproduction, cloning and genetics. CORE has been the most successful of all prolife groups in representing its ideas in the language of rights, discrimination and concern for children’s and women’s welfare. But its change of emphasis has not brought CORE any parliamentary gains. Instead, the organisation is using its funds to mount legal challenges to existing legislation, in the hope that the legislation will need to be re-examined by parliament.

ProLife Alliance

<i>Address</i>	PO Box 13395, London SW3 6XE
<i>Telephone</i>	020 7351 9955
<i>Website</i>	www.prolife.org

<i>Founded</i>	1997
<i>Membership</i>	No information provided.
<i>Leading figures</i>	Bruno Quintavalle
<i>Annual budget</i>	No information provided.

Describes itself as: 'Europe's first Pro-Life Political Party. We seek to ensure the right to life of all, the most basic and fundamental human right. To obtain this right, we will use only peaceful and democratic means. We are totally opposed to any form of violent protest.'

Activities: ProLife Alliance put up 55 prolife candidates in the 1997 general election and 37 candidates in the 2001 general election. Since the 2001 election, ProLife Alliance has concentrated upon legal challenges to relevant legislation, such as the recent case on the definition of an embryo in Human Fertilisation and Embryology Act 1990.

Comments: ProLife Alliance has a broader remit than CORE, covering issues relating to abortion and euthanasia as well as assisted reproduction and cloning. The group employs a very similar tactic, however, of mounting legal challenges to relevant legislation or policy decisions in an attempt to reopen debate in parliament.

Linacre Centre on Healthcare Ethics

<i>Address</i>	60 Grove End Road, St John's Wood, London NW8 9NH
<i>Telephone</i>	020 7806 4088
<i>Website</i>	www.linacre.org

<i>Founded</i>	1977
<i>Membership</i>	Friends scheme - not known how many
<i>Leading figures</i>	Helen Watt, director
<i>Annual budget</i>	£160,000

Describes itself as: 'The Linacre Centre exists to promote understanding of Catholic teaching on abortion, assisted conception, advance directives, contraception, euthanasia, genetic engineering and other issues in biomedical ethics.'

Activities: Academic research, publishing, bioethical training of health professionals.

Comments: Linacre has six staff and a number of academic heavyweights, such as John Finnis, on its board of Trustees. Dr Helen Watt is most active on issues relating to assisted reproduction and genetics and is the main prolife academic spokesman on these issues.

Student LifeNet

Address PO Box 30304, London NW10 2ZB
Telephone 07765 805742
Website www.studentlifenet.org.uk

Founded 2000
Membership No information provided.
Leading figures Fiona Pinto, Director
Annual budget No information provided.

Describes itself as: 'Student LifeNet is a national coalition of pro-life students, working together to protect and defend human life from the moment of conception until natural death.'

Activities: Student LifeNet publishes a bi-monthly newsletter and holds some protests, such as one outside an MRC stem cell research conference in September 2002 ('former embryos' T-shirts) and one at the Nice Summit (dressed as 'Tony's clones'). It has groups at universities around the UK. Its director, Fiona Pinto, stood in the 1997 general election for the ProLife Alliance.

Comments: Whilst Student LifeNet's aims are focused upon issues relating to abortion, its campaigns are directed more towards cloning.

Other Prolife groups

CARE for Life

Address 53 Romney Street, London, SW1P 3RF
Telephone 020 7233 0455
Website www.care.org.uk

Right to Life

Address PO Box 26264, London W3 9WF
Telephone 020 8992 7657
Website www.righttolife.org.uk

Centre for Bioethics and Public Policy

Address 51 Romney Street, London, SW1P 3RF
Telephone 020 7227 4706
Website www.cbpp.ac.uk