

Joint Press statement Genetic Interest Group and the Association of Medical Research Charities

embargoed: 5th April 2007

Press statement to accompany release of a letter to the Prime Minister, Tony Blair, signed by 223 medical research charities and patient organizations, following publication of the report from the Science and Technology Committee Inquiry into the Regulation of Hybrid and Chimera Embryos.

The letter to the Prime Minister is reproduced below, accompanied by the full list of signatories. Commenting on it,

Dr Sophie Petit-Zeman, Director of Public Dialogue, Association of Medical Research Charities (AMRC) says: "To our knowledge, a letter to government signed by 223 medical research charities and patient organisations is unprecedented. These groups are urging the Government to sanction research which has the potential to offer vital insights into a range of distressing conditions. The AMRC encourages public debate about medical research and respects and acknowledges sensitive feelings surrounding this type of research, but it is important to balance these against the medical benefits that might be lost if it were outlawed. Researchers tasked with unravelling and treating devastating disease see this work as potentially beneficial; allowing it to proceed is in the interests of patients and patient dignity."

Alastair Kent, Director of the Genetic Interest Group says:

"Families living with currently incurable and in many cases life threatening conditions rely on research to deliver new therapies. It is therefore vital that new avenues of research are explored. We hope that the Science and Technology Committee's findings and the strong consensus shown by this letter from patient groups will highlight the need for research involving cytoplasmic hybrids to be allowed to go ahead in the UK."

For more information please contact

Dr Sophie Petit-Zeman
Director of Public Dialogue
Association of Medical Research Charities (AMRC)
Tel: 07799 764475
Email: s.petit-zeman@amrc.org.uk

Nick Meade
Project & Policy Officer
Genetic Interest Group
Tel: 020 7704 3141
Email: nick.meade@gig.org.uk

Dear Prime Minister,

As members of two major national umbrella bodies involved in research for patient benefit, the Association of Medical Research Charities and the Genetic Interest Group, we are writing to you following the publication of the report from the Science and Technology Committee Inquiry into the Regulation of Hybrid and Chimera Embryos.

There has been growing disquiet in both the medical research community and among those who know too painfully the reality of illness - patients and families - about the possibility of a statutory ban on work involving the creation of these embryos as a source of stem cells for research into the causes and treatment of disease.

It is essential to encourage debate about medical research - we respect and acknowledge sensitive feelings surrounding this issue and applaud the public consultations that have and are taking place.

However, it is also essential to heed the views of researchers tasked with unraveling and treating disease. They highlight the need for this work because of the shortage of human eggs for medical research and because they see it as a vital avenue of inquiry which could greatly increase our understanding of serious medical conditions and ultimately lead to new treatments.

Organizations such as ours are committed to ensuring that well-regulated, carefully planned and high-quality work for patient benefit is encouraged, in a climate of public understanding and running alongside a background of ongoing public engagement. We know the reality of the conditions that this work could alleviate and urge you to allow it to proceed under these terms.

c.c. Caroline Flint MP, Minister of State for Public Health; Malcolm Wicks MP, Minister of State for Science and Innovation

Signatories

Action Cancer Action Medical Research Action on Addiction Action on Gilbert's Syndrome
Adrenal Hyperplasia Network Albinsim Fellowship ALD LIFE (support group for those affected
by Adrenoleukodystrophy and Adrenomyeloneuropathy) Alkaptonuria Society Alpha 1 Support
UK Alstrom Syndrome UK Alzheimer's Research Trust Alzheimer's Society AMEND -
Association for Multiple Endocrine Neoplasia Disorders Androgen Insensitivity Syndrome
Support Group (AISSG) Anirida Network Anorchidism Support Group (ASG) Antenatal Results

and Choices(ARC) Arrhythmia Alliance Arthritis Research Campaign Arthrogyrosis Group (TAG) Assert (the Angelman Syndrome Support Education and Research Trust) Association for Glycogen Storage Disease (UK) Association for International Cancer Research Association for Spina Bifida and Hydrocephalus (ASBAH) Asthma UK Ataxia - Telangiectasia Society Ataxia UK BackCare Barth Syndrome Trust Batten Disease Family Association Beckwith-Wiedmann Support Group BEHCETS Organisation Blackie Foundation Trust Brain Research Trust Breakthrough Breast Cancer Breast Cancer Campaign British Council for Prevention of Blindness British Heart Foundation British Liver Trust British Lung Foundation British Occupational Health Research Foundation British Pain Society British Porphyria Association British Retinitis Pigmentosa Society British Sjögren's Syndrome Association British Skin Foundation BUPA Foundation Cancer Research UK Cardiac Risk in the Young - CRY Cardiomyopathy Association CCHS Support Group (Congenital Central Hypoventilation Syndrome) CDLS Foundation (Cornelia De Lange Syndrome) Centronuclear and Myotubular Information Point CFS Research Foundation CGD Research Trust (Chronic Granulomatous Disorder) CHECT: Childhood Eye Cancer Trust (for families and individuals affected by Retinoblastoma) Chest Heart And Stroke Scotland Children Living with Inherited Metabolic Diseases (CLIMB) Children with Leukaemia Children's Liver Disease Foundation Children's Mitochondrial Disease Network Chronic Disease Research Foundation Chronic Granulomatous Disorder Research Trust Circulation Foundation (British Vascular Foundation) CMT UK (Charcot-Marie-Tooth Disease) Cogent Trust Cohen Syndrome Support Group Congenital Adrenal Hyperplasia Support Group CORE (Digestive Disorders Foundation) Costello Support Group Cri Du Chat Syndrome Group Cystic Fibrosis Trust Deafness Research UK (aka Hearing Research Trust) Diabetes Research and Wellness Foundation Diabetes UK Down's Heart Group Dyskeratosis Congenita Society East London Branch Sickle Cell Society Ectodermal Dysplasia Society Ehlers-Danlos Support Group EMF Biological Research Trust Epilepsy Research Foundation Eyeless Trust Fapgene (Familial Adenomatous Polyposis and Gardners Syndrome) Fight for Sight (British Eye Research Foundation) Foundation for Liver Research Foundation for the Study of Infant Deaths Fragile X Society FSP Support Group FuchsFriends UK Fund for Epilepsy Galactosaemia Support Group Gauchers Association GeneAid Gorlin Syndrome Group Guy's and St Thomas' Charity Gwent Huntington's Disease Support Group Haemochromatosis Society Headlines (the Craniofacial support group) Healing Foundation Heart Haven HITS (UK) Family Support Network HME Support Group (Hereditary Multiple Exostoses Support Group) Huntington's Disease Association Hypermobility Syndrome Association Hypertension Trust Inspire Foundation (aka Integrated Spinal Rehabilitation Foundation) International Autistic Research Organisation International Spinal Research Trust Jennifer Trust for Spinal Muscular Atrophy Juvenile Diabetes Research Foundation UK Kidney Research UK Klinefelter Organisation (UK) Laurence Moon Bardet Biedl Society Lister Institute of Preventive Medicine Little Foundation Lowe Trust Ludwig Institute for Cancer Research Making it Better - Daniel Courtney Trust (Microvillous Atrophy support group) Manchester Sickle Cell and Thalassaemia Centre Marfan Association UK Marie Curie Research Institute MAX Appeal (Di George Syndrome / VCFS and 22q11.2 deletion) Medical Research Scotland (formally Scottish Hospital Endowments Research Trust, SHERT) Meningitis Research Foundation Meningitis Trust Meningitis UK (Registered as Spencer Dayman Meningitis UK) Migraine Trust Mosaic Down Syndrome UK Motor Neurone Disease Association Mowat-Wilson Syndrome Support Group Multiple Sclerosis Society of Great Britain and Northern Ireland Muscular Dystrophy Campaign Muscular Dystrophy Support Group Myotonic Dystrophy Support Group Narcolepsy Association (UKAN) NASPCS (charity for incontinent and stoma children) National Association for Colitis & Crohn's Disease National Eczema Society National Eye Research Centre National Osteoporosis Society National Sickle Cell Programme NemaLine Myopathy Neuro-Disability Research Trust (formerly Living Again) Neurofibromatosis Association Niemann-Pick Disease Group (UK) North West Cancer Research Fund Northern Ireland Chest Heart & Stroke Association Northern Ireland Leukaemia

Research Fund Novartis Foundation NPS UK (Nail Patella Syndrome) NSPKU (charity for those with Phenylketonuria PKU) Nuffield Foundation Nystagmus Network Ohdo Syndrome Family Network OSCAR (Organisation for Sickle Cell Anaemia - Reading) Osteopetrosis Support Group Parkinson's Disease Society of the UK PBC Foundation Pemphigus Vulgaris Network Peutz Jeghers Syndrome Support Group (general website) Pick's Disease Support Group PKD Charity (polycystic kidney disease) Plagiocephaly Care UK PPUK (Parent Project UK fighting for a cure for Duchenne Muscular Dystrophy) Prader Willi Syndrome Association UK Primary Ciliary Dyskinesia Family Support Group Primary Immunodeficiency Association (PiA) Progressive Supranuclear Palsy Association Prostate Cancer Research Foundation Psoriasis Association Psoriatic Arthropathy Alliance PXE Support Group Queen Victoria Hospital Blond McIndoe Research Foundation RAFT (Restoration of Appearance & Function Trust) Remedi Research into Ageing Restricted Growth Association Rett Syndrome Association UK Roy Castle Lung Cancer Foundation Royal College of Surgeons of England Rubinstein Taybi Support Group SADS UK (The Sudden Adult Death Trust) Saint Peter's Trust for Kidney, Bladder & Prostate Research Samantha Dickson Brain Tumour Trust Scottish Huntington's Association Seriously Ill for Medical Research Shwachman Diamond Support Sickle Cell and Young Stroke Survivors Society For Endocrinology Society for Mucopolysaccharide Diseases SOFT UK (Support Organisation For Trisomy 13/18 and related disorders) Sparks (Sport Aiding Medical Research for Kids) STEPS Stickler Syndrome Support Group Stroke Association Syndromes without a name (SWAN) Tar Support Group Tay Sachs and Allied Diseases Association Telangiectasia Self Help Group Tenovus TOFS (Tracheo-Oesophageal Fistula Support, helping children born unable to swallow) Tommy's The Baby Charity Treacher Collins Family Support Group Triple X Family Network Support Group Tuberos Sclerosis Association Turner Syndrome Support Society (UK) Tyneside Leukaemia Research Association UK Thalassaemia Society Ulster Cancer Foundation Unique - The Rare Chromosome Disorder Support Group Wellbeing of Women WellChild Wessex Medical Trust (aka Hope) William Harvey Research Foundation Williams Syndrome Foundation Limited Wolf Hirschhorn Syndrome Support Group UK World Cancer Research Fund Worster Drought Syndrome Support Group XLH Network XLP Research Trust XP Support Group (Xeroderma Pigmentosum) Yorkshire Cancer Research

Ends

Notes to Editors

- **The Genetic Interest Group (GIG)** is a national alliance of organisations with a membership of over 120 charities that support children, families and individuals affected by genetic disorders.
- Our 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.
- Individually, many genetic conditions are rare and as such it is difficult to raise their profile and the needs of those affected by them. GIG provides a common platform from which effective programmes to raise awareness, inform the media and influence government, industry and the NHS can be launched
- As an organisation focusing on issues of policy and practice GIG keeps an active watch on developments in the UK and Europe that will influence the effective transfer of knowledge and understanding into products and services for families that are supported by our member groups.

- In a potentially controversial field like genetics GIG provides a strong voice advocating the benefits of scientific progress in understanding the contribution being made now and that will be made in the years to come for improving health and combating many currently incurable diseases.

Registered Office:
The Genetic Interest Group
Unit 4D, Leroy House
London
N1 3QP

A Registered Charity (Number 803424)