

Appendix: literature used in the policy review

Public opinion

The HFEA commission its own research into public opinion formation: *Attitudes to embryo selection to produce tissue donors*, Opinion Leader Research, June 2004

Expert opinion

The HFEA received expert opinion from the UK Childhood Cancer Study Group and the following individuals:

Phil Darbyshire *Consultant Paediatrician, Birmingham Children's Hospital*

Eliane Gluckman *Co-ordinator, Eurocord, Paris*

Anette Hewitt *Clinical Nurse Specialist, Bone Marrow Transplant Unit, Great Ormond Street Children's Hospital*

Rebekah Lwin *Consultant Clinical Psychologist, Alder Hey Hospital*

Professor Alejandro Madrigal *Scientific Director, Anthony Nolan Research Institute*

Diane Melvin *Consultant Clinical Psychologist, Great Ormond Street Children's Hospital*

Christine Navarrete *Consultant Clinical Scientist, North London Blood Transfusion Centre, National Blood Service*

Derwood Pamphillion *Medical Advisor, National Blood Service*

Professor Proctor *Professor of Haematological Oncology, Leukaemia Research Centre, Newcastle*

Irene Roberts *Professor of Paediatric Haematology, Imperial College, London*

Rod Skinner *Senior Lecturer in Paediatric Oncology, University of Newcastle*

Colin Steward *Chairman of the UK Childhood Cancer Study Group, Bristol Royal Hospital for Children*

Paul Veys *Consultant Bone Marrow Transplantation, Great Ormond Street Children's Hospital*

Ajay Vora *Consultant Paediatric Haematologist, Sheffield Children's Hospital*

Case law and statute

Re J (Specific Issue Orders: Child's Religious Upbringing and Circumcision) [2000] 1 FLR 571

Re F (Mental Patient: Sterilisation) [1989] 2 WLR 1025

Re Y (Mental Incapacity: Bone Marrow Transplant) [1996] 2 FLR 787

Re W (a minor) (medical treatment) [1992] 4 All ER 627

Gillick v West Norfolk and Wisbech Health Authority [1985] 3 All ER 402

Hart v Brown (1972) 289 A 2d 386 (Conn Sup Ct)

R (on the application of Quintavalle) v HFEA [2002] EWHC 2785 (Admin)

R (on the application of Quintavalle) v HFEA [2002] EWCA Civ 667

Family Law Reform Act 1969

European Convention on Human Rights and Biomedicine

WHO Guiding Principles on Human Organ Transplantation

Children Act 1989

Opinions of ethics committees and organisations

British Medical Association *BMA Ethicsbrief* Issue 65, Annual Representatives Meeting 2003, and Issue 66, September 2003

Human Genetics Commission, Meeting of Genetic Testing Sub-group: 16 February 2001

British Fertility Society Response to the HFEA and ACGT Consultation Document on Preimplantation Diagnosis British Fertility Society, March 2000

'Taskforce 5: preimplantation genetic diagnosis' ESHRE Ethics Task Force *Human Reproduction* (2003) 18 (3) 649-651

Report of the IBC on preimplantation genetic diagnosis and germline intervention UNESCO International Bioethics Committee, 24 April 2003

Declaration of Ottawa on the Rights of the Child to health care, World Medical Association, October 1998

Reproduction and Responsibility: The Regulation of New Biotechnologies, President's Council on Bioethics, March 2004

Ethical guidelines on the use of reproductive technology in clinical practice and research, National Health & Medical Research Council (Draft) February 2003

Tissue typing with preimplantation genetic diagnosis, Infertility Treatment Authority, reviewed January 2003

Report by the working party on the Protection of the Human Embryo and Foetus, Council of Europe, June 2003

Microinsemination and pre-implantation genetic diagnosis, Danish Council of Ethics (2003)

Reflections concerning an extension of preimplantation genetic diagnosis National Ethics Committee for Life Sciences and Health (France), July 2002

Prenatal testing – new developments and ethical dilemmas, Royal Netherlands Academy of Arts and Sciences, symposium of 18 June 2003, report published 2004

Literature review

The HFEA identified the following science and ethics papers as part of its literature review.

Science papers

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Pediatrics Vol. 106 No.4 October 2000, 650-653 Neonatal outcome of preimplantation genetic diagnosis by polar body removal: the first 109 infants. Charles M Strom et al.

Blood. 2003 Dec 15;102(13):4290-7. Epub 2003 Aug 14 Unrelated cord blood transplantation for childhood acute myeloid leukemia: a Eurocord Group analysis. Michel G, Rocha V, Chevret S, Arcese W, Chan KW, Filipovich A, Takahashi TA, Vowels M, Ortega J, Bordigoni P, Shaw PJ, Yaniv I, Machado A, Pimentel P, Fagioli F, Verdeguer A, Jouet JP, Diez B, Ferreira E, Pasquini R, Rosenthal J, Sievers E, Messina C, Iori AP, Garnier F, Ionescu I, Locatelli F, Gluckman E; Eurocord Group.

Br J Haematol. 2001;112:981-987 Cord blood transplantation from HLA-mismatched unrelated donors as a treatment for children with haematological malignancies. Ohnuma K, Isoyama K, Ikuta K, Toyoda Y, Nakamura J, Nakajima F, Tsuchida M, Ohira M, Suminoe A, Hara T, Nishihira H.

N Engl J Med. 2004 May 6;350(19):1960-9. Cord-blood transplants from unrelated donors in patients with Hurler's syndrome. Staba SL, Escolar ML, Poe M, Kim Y, Martin PL, Szabolcs P, Allison-Thacker J, Wood S, Wenger DA, Rubinstein P, Hopwood JJ, Krivit W, Kurtzberg J.

J Pediatr. 2001 Apr;138(4):570-3. Unrelated umbilical cord stem cell transplantation for X-linked immunodeficiencies. Ziegner UH, Ochs HD, Schanen C, Feig SA, Seyama K, Futatani T, Gross T, Wakim M, Roberts RL, Rawlings DJ, Dovat S, Fraser JK, Stiehm ER.

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Bone Marrow Transplant. 2001 Jul;28(1):110-2. Unrelated cord blood transplantation in a Fanconi anemia patient using fludarabine-based conditioning. de Medeiros CR, Silva LM, Pasquini R.

J Pediatr Hematol Oncol. 1999 May-Jun;21(3):237-9. Fludarabine-based protocol for human umbilical cord blood transplantation in children with Fanconi anemia. Aker M, Varadi G, Slavin S, Nagler A.

Bone Marrow Transplant. 2001 Apr;27(7):767-9. Prompt and durable hematopoietic reconstitution by unrelated cord blood transplantation in a child with Fanconi anemia. Yoshimasu T, Tanaka R, Suenobu S, Yagasaki H, Yoshino H, Ueda T, Hisakawa H, Ishii T, Mitsui T, Ebihara Y, Manabe A, Iseki T, Maekawa T, Nakahata T, Asano S, Tsuji K.

Blood. 2004 Feb 1;103(3):1147-51. Successful hematopoietic stem cell transplantation for Fanconi anemia from an unaffected HLA-genotype-identical sibling selected using preimplantation genetic diagnosis. Grewal SS, Kahn JP, MacMillan ML, Ramsay NK, Wagner JE.

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Blood. 2003 15;101(6):2137-43. Related umbilical cord blood transplantation in patients with thalassemia and sickle cell disease. Locatelli F, Rocha V, Reed W, Bernaudin F, Ertem M, Grafakos S, Brichard B, Li X, Nagler A, Giorgiani G, Haut PR, Brochstein JA, Nugent DJ, Blatt J, Woodard P, Kurtzberg J, Rubin CM, Miniero R, Lutz P, Raja T, Roberts I, Will AM, Yaniv I, Vermynen C, Tannoia N, Garnier F, Ionescu I, Walters MC, Lubin BH, Gluckman E; Eurocord Transplant Group.

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