

# Scottish Council on Human Bioethics

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**Date: 4 July 2007 – Human Fertilisation and Embryology Authority**

## **Consultation Paper on multiple births after IVF**

### **Consultation response on behalf of the Scottish Council on Human Bioethics:**

The **Scottish Council on Human Bioethics** (SCHB) is an independent, non-partisan, non-religious registered Scottish charity comprising doctors, lawyers, psychologists, ethicists and other professionals from disciplines associated with medical ethics.

The SCHB subscribes to the principles set out in the **United Nations Universal Declaration of Human Rights** which was adopted and proclaimed by the UN General Assembly by resolution 217A (III) on 10 December 1948.

The SCHB is grateful to the HFEA for this opportunity to respond to the consultation entitled **The Best Possible Start to Life**. It welcomes the HFEA's intent to promote public consultation, understanding and discussion on multiple births after IVF.

In addressing the consultation, the SCHB has formulated the following responses, which can be made publicly available by the HFEA:

#### **1. What is your interest in multiple births after IVF?**

The Scottish Council on Human Bioethics (SCHB) is an independent charity with the following remit:

- To collect and evaluate evidence and information relating to ethical issues in medicine from which to inform public debate in Scotland;
- To engage, assist and advise Scottish legislators, fellow professionals and other interested parties with ethical analysis in medicine and comment on these issues;
- To respond to media interest in Scotland by the release of relevant and reliable information and comment;
- To encourage Scottish society to engage in ethical discussions of relevant topics in medicine and biology.

#### **2. Do you think there is too much or not enough emphasis on the health risks for twins and their mothers?**

Not enough emphasis

##### **Why? Please give your reasons below:**

The SCHB believes that in the field of fertility there needs to be more emphasis on the health risks.

The work of the HFEA is very important since it addresses human beings and persons. Any business has to audit results and make them known to the prospective clients. This is the same with the HFEA, when promoting their products, they have to be clear about the weaknesses and drawbacks.

Up to date information has to be made available to couples. Many couples are very vulnerable as they approach IVF with only one goal in view, without really contemplating all the consequences. As part of their preparation, it may be appropriate to suggest to parents that they should not 'want a child at **any** cost'. Their wish for a child may be to satisfy their own desire to be parents. They may not be able to think beyond this, as they see a child to be the great ambition in their lives. They need to consider that any child they bring into the world will live with the problems, as well as benefits, accorded to them, genetically and environmentally, including all the circumstances of the petrie dish and the birth: physical, physiological and psychological.

The SCHB believes that couples should be counselled to consider the different ways in which they, as couples, can still lead a fulfilling role in life, if they were to remain childless. This should be emphasised because of the considerable chance that they may not end up with a 'take home baby'. Their relationship is paramount in their own lives and in the life of a possible child, since marital break-up, can adversely affect children.

The importance of the relationship of the couple should therefore be placed above the perceived need for children. This is obviously all the more important if there is a risk of multiple pregnancy, where the stresses can be greater for children and their mothers.

While it is important that the fertility sector responds appropriately to the risks in multiple pregnancies, the SCHB does not believe that it is something that needs more emphasis outside of that sector, where there is no control over the occurrence of multiple pregnancy. It would not be helpful to make the possibility of multiple pregnancy more intimidating to all prospective mothers, as this could create more stress, as well as impact on abortion rates.

However, it is clear that the issue needs to be addressed in the fertility sector, and within those bounds, the SCHB agrees that there could be more emphasis on the fact that there are risks attached to multiple pregnancy. This information should be presented to patients not by the clinics carrying out the treatment, but before that point in the process is reached.

**3. Who do you think should decide which women should have just one embryo transferred during IVF?**

Professional bodies (organisations that represent fertility practitioners) through recommendations to fertility practitioners.

**Please give reasons for your answer:**

The SCHB believes that education regarding the advantages of singleton pregnancy should be emphasised. The risks have been delineated in the document and seem to be clear to the HFEA. These should be considered before the 'importance' of the success of implantation or take home baby rate. The parents may be too emotionally involved and too enthusiastic to make clear decisions.

Rather than publishing headline success rates in a league table, the HFEA should publish both cumulative success rates and multiple pregnancy rates, so that patients can make informed choices based on the information they have regarding the desirability of singleton pregnancy.

**4. Do you think the current guidance on embryo transfer by the HFEA is about right?**

No, it is not strict enough and allows the high number of twin pregnancies to continue. The well-being of the child should be paramount.

**5. Part 4 of this document contains regulatory options for the HFEA – which one do you prefer?**

The SCHB believes that, when properly educated about the risks associated with multiple pregnancy, patients will favour clinics with a lower rate of multiple birth.

In order for couples to give valid consent, all the information needs to be made available to them, including all of the possible risks to the mother, father, increased risk of relationship breakdown, possible and known health risks to the child, children and subsequent generations. When faced with the data, they may make a more informed choice.

**6. The Expert Group investigating the question of multiple births after IVF and the HFEA have discussed some possible obstacles to change. Do you think that any of the factors listed below make it harder to effectively reduce the proportion of twin pregnancies after IVF?**

The SCHB believes the following factors are barriers:

- The lack of understanding of the risks involved in multiple pregnancies by patients and/or fertility practitioners;
- A desire for twin pregnancies by some patients and fertility practitioners;
- The way the HFEA produces and presents outcome data for fertility clinics (pregnancy rate per fresh cycle started);
- Competition between fertility centres.

**Give reasons for your choices:**

Presenting league tables of headline success rates makes it in the interests of the clinics to implant as many embryos as they can, and so this way of publishing information is unhelpful.

**7. Is there anything else you want to tell the HFEA about the issues raised in this consultation document?**

The SCHB believes that hormones should only be used very carefully since they stimulate superovulation, which presents significant risks to the patient such as with ovarian hyper stimulation syndrome, (OHSS).

Everything should be evidence-based and hopefully studies are being undertaken to track the proven and, so far unproven risks of IVF, to the mother, the children and further generations. This is important for pre-treatment counselling and valid consent. This does not relate just to the risk of twins, but all IVF children and subsequent generations.

For example, it has been suggested that other risks exist, such as the possibility of an increased risk of ovarian cancer for IVF patients in later life, but a connection between IVF and cancer has never been proven.

If the HFEA wants to conduct a meaningful publicity campaign, which would help to reduce the need for public funding in this area, it would be perhaps best guided to encourage couples to start their family when their fertility is at its peak, rather than waiting until their late 30's and after all their life adventures. Society has recently been hit with the headlines of how one third of professional women never have any children, because they wait until it is too late.