

Question 1: YES.

The Genetic Interest Group (GIG) believes that the supply of new stem cell lines should continue to be considered as a national strategic issue provided that this is the best scenario to ensure:

- that stem cell research remains a high priority for funding organisations.
- that there is a coordinated approach, reducing bureaucracy and ensuring that novel research can proceed as quickly as possible.
- that this structure will provide a good communication framework between all stakeholders, including patients, and that their interests and priorities are taken into account.

Question 7:

The Genetic Interest Group (GIG) was involved in the Stem Cell Public Dialogue Stakeholder workshop in July of this year. We support the National Public Dialogue Project that this workshop was aimed at informing. This is an example of proactive public education/dialogue, which we believe to be more fruitful than a dialogue that reacts to public concerns and media hype.

GIG often communicates with patients and the public on issues surrounding stem cell research, most recently during the HFEA's consultation on the use of cytoplasmic-hybrid embryos to produce embryonic stem cells. We believe that the more the public understands about stem cell research in general, the more likely they are to take a reasoned and proportionate position on any issues pertaining to stem cell research.

The best way to ensure that the public's understanding of stem cell research improves is by promoting communication between researchers and the public (in as direct a manner as possible). Organisations such as the Medical Research Council (MRC) could facilitate this by encouraging and assisting research scientists to describe their work as accurately as possible in lay terms, and ensuring that the descriptions are put into context with explanations of how discoveries may affect the patient. Communication with the public should emphasise that research is by definition an exploration of the unknown, and that predictions for future uses of research findings are hypothetical.

Press coverage of stem cell research can also be improved. The coverage can be overwrought whether the report is of good news or bad, and can fail to adequately explain the reasoning behind such research and its potential benefit to patients. Further use of organisations such as the Science Media Centre (SMC) to ensure balanced and sober coverage of developments in the field would greatly assist a positive public perception of stem cell research.

Question 8:

The Genetic Interest Group (GIG) is an umbrella organisation working for more than 130 member groups, who support patients of inherited conditions and their families. Many of the conditions represented by our member groups are incurable and intractable, with no cure or treatment on the horizon. GIG speaks from the perspective of those who have a keen interest in the undertaking of high quality ethically sound biomedical research into the links between genetics and human health and disease. GIG's members and the families they support depend on research, and its application in the form of new products and services to eliminate or alleviate the impact of diseases which currently cause chronic ill health, frequently progressive disability and sometimes premature death.

Our members are aware that so far there has been no treatment delivered from embryonic stem cell research, and there is none forthcoming. Despite this, patients look towards this research with hope, and even expectation. GIG supports the continued research into stem cells as a potential source of therapy for serious diseases. It is vital that their promise is given adequate research attention to allow their huge potential to save lives to be examined.