Modifying germlines – or not?

Designing our Descendants: The Promises and Perils of Genetic Modification

Edited by Audrey R. Chapman and Mark S. Frankel

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In January 1998, the Programs of Dialogue on Science, Ethics and Religion, and of Scientific Freedom, Responsibility and Law at the American Association for the Advancement of Science (AAAS) began examining the social issues raised by the Human Genome Project and reproductive technologies. With support from the Greenwall Foundation, a diverse group of experts on science, religion, bioethics and public policy performed multidisciplinary dialogues over a period of two and a half years on the implications of research on inherited genetic modifications and its applications. The AAAS program officers Audrey Chapman and Mark Frankel, explicitly intended to reach beyond the walls of academia to stimulate wider public discussion of these issues. A shorter AAAS report in 2000, *Human Inheritable Genetic Modifications: Assessing Scientific, Ethical, Religious and Policy Issues* (edited by Frankel and Chapman), began the discussion and is available through the AAAS website for free. The second product of this extensive project, *Designing our Descendants: The promises and perils of genetic modification* (also edited by Frankel and Chapman) expands on the earlier work and seeks to reach an even wider audience.

All too often experts in areas such as science, religion, bioethics and policy that are brought together to discuss these wide-ranging public issues remain separate or there is just a token representative from each discipline. Alternatively, there may be an isolated event, one set of discussions and then the experts retreat into separate enclaves to write. Rarely is much effort spent developing communication and collaborative understanding across disciplines. *Designing our descendants* is an exception, and reflects the collaborative effort and unique commitment of the program officers and their panel of experts. The AAAS and the Greenwall Foundation should be congratulated on the results.

Opening with a useful overview by the editors and followed by a chapter providing an important discussion of definitions, a set of five

chapters exploring the science and technology of genetic modification, nine chapters introducing issues of ethics, religion and law, and finally, four chapters exploring policy issues; this collection substantively and rigorously covers a broad range of topics from this debate. The contributors suggest we use this as a starting point for public discussions of the issues raised. Gene modification in somatic cells is one thing, but inheritable modifications to the germ line raise special questions that deserve the directed scrutiny provided here. The fact that researchers do not see probable cases where such inheritable modifications will have therapeutic value, combined with the general agreement that they should only be justified in cases of therapeutic value, calls both the scientific and medical applications into question. But rather than setting aside this possibility, the authors work to probe the types of possible cases that might result in the legitimate use of this technology. The discussion of these possible scenarios also suggests the need for clearly articulated guidelines. This general conviction leads some authors and the group as a whole (or at least a majority agreement, we are told) to offer recommendations from the perspectives of both policy and practice.

Although discussions in the book centre on the US, their considerations and conclusions transport to an international arena. Recommendations call for stimulating public discussion of the implications, values and policy in anticipation of scientific developments, rather than after we are already faced with scientific realities. They urge us to establish a reflective and effective system of guidelines and oversight procedures that result in setting standards that balance scientific freedom and responsibility. A logical next step would be to take these recommendations and develop a follow-up project exploring comparative national contexts and their individual constraints.

For example, Julie Gage Palmer and Robert Cook-Deegan suggest we follow the model set by the Recombinant DNA Advisory Committee (which oversaw somatic cell gene transfer until 1995) with a defined process for evaluating any proposed research or application. Cynthia Cohen places the discussion in the context of reproductive rights, suggesting regulation and oversight that would both enable and constrain the work. In contrast, Frankel and Michele Garfinkel raise questions of how and whether we should allow market forces to control our decisions about this technology. Finally, Frankel and Chapman outline a framework for policy recommendations, and end with a summary of (apparently largely) shared findings, concerns and recommendations.

This is not the usual collection of stapled-together reflections on bioethics issues, but a truly collaborative set of excellent contributions to a project that is much more than the sum of its parts. The proposed Consent Form for Participation in studies involving inheritable genetic modification, the report of major findings and the policy recommendations are important, and should provide the basis for further informed discussion. The results are balanced, and neither biased towards pursuing science at any cost nor towards imposing restrictions for knee-jerk intuitive reasons. This volume and the larger project advance the dialogue about science and society, just as its editors and participants intended, and the product should interest everyone concerned with the intersection of science and society.

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