BIOETHICS AND GOVERNMENTS
Comparing French and American Responses to New Human Technologies

The “Association Française contre les Myopathies” and the cloning debate
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AFM stands for “Association Française contre les Myopathies”—it means the French Association against Muscular Dystrophies, with emphasis on “against.” This patients’ organization funds a large amount of biomedical research on neuromuscular disorders (and a few other genetic diseases) with money collected by our highly successful Telethon (over 100 million dollars annually). Unlike many other large charities, the executive board is composed entirely of patients affected by these diseases and their families. Our Scientific Council and a large network of external experts make recommendations on the scientific merit of projects submitted to our Grant Programs, but the strategic decisions are made by those directly affected by these diseases. The principle that the decision-making power must remain with patients and their families is very basic to AFM (and sometimes leads to misunderstandings).

Although AFM participates in public and political debates, and takes part in patient advocacy, often in concert with other associations (for instance, France is far behind the US in terms of accessibility for disabled persons), our position in the ethical debates is quite different, a lot less militant than it is in other areas of action.

It is AFM’s belief that it is not the role of associations to take a political position on this sort of ethical question, but rather to educate affected patients and their families and to encourage public reflection and debate. It is up to individuals to make their own decisions about these questions, and it would be difficult, even for an association of patients, to arrive at a consensus view. These questions belong in the public domain.

Roles and responsibilities of scientists and other experts are different from those of patients, in the view of AFM. In 2002, AFM sponsored a debate held at their new Convention Center entitled: “Stem Cells and therapeutic cloning: experts meet patients” (“Cellules souches et clonage thérapeutique: les experts face aux malades”). There was a feeling that participants in the stem cell debate in France until then were mainly a somewhat closed circle of scientists, lawyers, philosophers and politicians. Patients, who would be the possible beneficiaries of this research if it is allowed to go forward, had been left out. The objective of this initiative was to bring the debate out into the open, and to allow the voices of the patients and their families to be heard. AFM tried to create a sort of “Citizen’s Forum”-- not one in which all segments of society would participate but rather limited to those directly affected by the potential results of stem cell research. The timing was important, because the debate took place just when the French law on bioethics was due for revision.

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The debate consisted of presentations by various experts to a panel of 12 representatives from patient organizations, who then formulated a series of recommendations. It was intended to be a sort of “Consensus Conference” based on a model which was used for the first “Citizens Conference” which was organized by the French government in 1988 on the topic of genetically modified organisms. AFM hired a consulting firm, Altao, which was specialized in organizing this type of conference, to select the panel and to help organize the debate. The idea was to create a panel of citizens from all walks of life, but limited to those affected by diseases that could benefit from the results of stem cell research. To recruit members of the panel, invitations were sent to about 300 organizations to solicit volunteers. Volunteers were not supposed to have any vested interests (links with economic, political or scientific interests) or firm pre-conceived ideas about stem cell research; they were selected on the basis of “open-mindedness,” and their capacity to represent an ensemble of patients and not just their own associations. Their characteristics are shown below:

1. **Characteristics of the panel:**

- Age: 28-68 years old,
- Six men, six women,
- Half were patients themselves, half were parents of patients,
- No firm pre-conceived opinions on stem cell research,
- Should not be considered exclusively as spokespersons for their own associations.

2. **Professions:**

- Documentalist
- Teacher (2)
- PhD student
- Security guard
- Personal assistant
- Professional care-giver
- Civil servant
- Technician (retired)
- Salesman (retired)
- Commercial director (retired)
- Computer engineer
3. Diseases affecting panel members or their families (total is 14 because two panel members were alternates):

- Naevus
- Ankylosing spondylarthitis
- Fanconi’s anemia
- Cutis laxa
- Sickle-cell anemia
- Charcot-Marie-Tooth disease
- Retinitis pigmentosa
- Kennedy’s disease
- Cerebellar syndrome
- Desmoid tumor
- Huntington’s disease
- Oculo-cutaneous albinism
- Duchenne muscular dystrophy
- Neurofibromatosis

4. Organization:

The debate was preceded by two information sessions each of which lasted one day for the panel members.

Presentations were made by scientists, clinicians, lawyers, and a Professor of Philosophy; some of these had specific interest in or were specialized in bioethics.

The public debate took place two weeks later, and included presentations by a different group of scientists, clinicians, philosophers, law professors, legislators, etc. One was a representative from the biotechnology industry, and at least one was a practicing Catholic.

The debate itself consisted of three sessions of presentations by experts, articulated around three main topics. Panel members formed a sort of “jury”, and there was a question session following each presentation.

5. Session topics:

- “Research on stem cells: hopes and limits”
- “The human embryo: object or research subject?”
- “Regulation of stem cell research-Why? How?”

Panel members formed a sort of “jury” and there was a question session following each presentation.
6. Main recommendations of the jury are as follows:

- No ethical problems in research on adult stem cells
- Necessity of regulation for research on cell therapies
- Authorization for utilization of embryonic stem cells within a strict regulatory and legislative framework. Representation of patient associations on governmental regulatory body.
- Utilization of cloning only for therapeutic purposes, and always within the same legislative and regulatory framework.
- Total prohibition of human cloning for other than therapeutic purposes.
- Development and implementation of a policy for research.
- Protection and information for donors.
- Authorization of import of stem cell lines under specific conditions.

These recommendations were sent to Senator Francis Giraud, who was in charge of the bioethics law project in the French Senate, and also addressed to the President of the Republic, government Ministers of Health and Research, and members of Parliament. This was the first time in France that representatives of civil society made their voices heard in a public health debate in which they were especially concerned.

It is now three years later, and AFM is funding France’s main stem cell initiative, a group called “I-Stem” which is currently occupying AFM’s former cafeteria. It is clear that all the authorizations required by France’s new bioethics law had to be obtained by the Principal Investigator (Marc Peschanski), and the first imported stem cell lines arrived in this laboratory in August. The roles of the scientists and of AFM are quite separate.

When ethical questions arise, we should consider two dimensions, specific issues which apply to the individual or a group of individuals, and those which apply to society as a whole. In the domain of neuromuscular diseases, the organization of meetings of experts to develop recommendations for good practices is an example of AFM’s efforts to define norms in a given context and time period. In situations in which conflicts between the needs of the individual and the values of society are likely to occur, the responsibility of AFM is not to
define norms for civil society, but to provide individuals affected by neuromuscular diseases and their families with the resources (information and support) to make informed decisions.