FROM LEGISLATION TO DEBATE:
THE REGULATION OF ASSISTED REPRODUCTION, HUMAN CLONING, AND EMBRYONIC STEM CELL (ESC)
RESEARCH IN FRANCE

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Introduction

In 2000, the jurist Nan T. Ball published one of a very limited number of analytical articles on the 1994 French bioethics laws (FBLs). In a refreshing departure from traditional portraits of a top-down, rigid political institutional context, Ball analyzed, through a literary and historical prism, the importance of Enlightenment ideals in the relationship between family, nature, and society, and how those ideals played as much of a role as institutional imperatives. Her juxtaposition of some of Jean-Jacques Rousseau’s key writings to contemporary French discourse in the debates surrounding the FBLs opens the reader’s eyes to other avenues of comprehension as to how these laws came to be. Though her emphasis on the legacy of the Enlightenment as a major vector in the drafting of the FBLs is a matter of debate, her argument nonetheless points to the relevance of looking elsewhere than to institutional forces.

This essay will discuss the role of these institutional forces in the shaping of the FBLs, but in so doing, will also attend to the evolving contemporary socio-political landscape that will eventually exert as much of an influence on the institutions as the latter did on legislation. The most important of these institutions is of course the French National Consultative Ethics Committee for Health and Life Sciences (CCNE), followed by the State Council (Conseil d’Etat; simultaneously an advisor to the government, evaluating bills prior to their passage, and the highest administrative tribunal), the Constitutional Council (Conseil constitutionnel; to a certain extent the equivalent of the US Supreme Court, but which evaluates the constitutionality of a bill before it is passed), and finally the French Parliament.

In short, the argument will be made that the role of the CCNE and certain political and regulatory institutions were prominent in the period preceding the 1994 laws, beginning with the role of President François Mitterrand in the creation of the CCNE in 1983, but from then until now, especially with the FBL’s revisions in August 2004, several new parameters entered the picture, and had a decided impact on initial institutional objectives. They include:

- the role played by several events (the birth of “Amandine”, that of Dolly, the contaminated blood scandal, the Mad Cow disease, the passage of the PACs, the Perruche and Vincent Humbert affairs);

- the increasing activity, and one could even say, militantism of certain members of the civil society (especially scientists, intellectuals, and specific interest groups);
- increasing media coverage of bioethical issues, and last but not least;
- the role the image/perception of the United States plays in what is commonly referred to as pro or anti-Americanism, that is to say positions adopted by leading public figures, scientists, intellectuals, and decision-makers either for or against (the portrayal of) what occurs in the United States, and how those positions shape or reflect an increasingly aware public opinion.

Leading up to the 1994 FBLs

Prior to the passage of the 1994 FBLs, the traditional analysis of regulatory procedures in France is appropriate, one that customarily describes the French regulatory system in general and its judicial system in particular as top-down oriented, frozen within the strict application of codes, and emphasizing the general interest. This is often compared to the Anglo-American or Anglo-Saxon systems, described as being highly pragmatic, flexible, and emphasizing individual rights. It is important to remark, however, that in the more specific realm of bioethics, this comparison does not stand when one looks at the UK and US system, as one knows the UK system with its HFEA does not shy before state control. Nor does the comparison hold when one looks at the French situation from 1994 to the present day, a matter to be addressed shortly.

Albeit, the differing juridical and philosophical approaches between the United States and Europe certainly play a role. It is argued that Europeans situate legal issues, notably those resulting from biomedical practices, within the framework of supranational human rights laws. Indeed, the Council of Europe's Convention on Human Rights and Biomedicine, signed in 1997, is rooted in a particular philosophical tradition and is shaped, in various areas, by natural rights philosophy and the Kantian/Rawlsian theory of justice. Thus, the overriding themes of human dignity and bodily inviolability in the Convention as well as in the FBLs prevail over that of individual autonomy. This, of course, is to be distinguished from the United States approach that attempts to situate the consequences of biomedical practices within traditional categories of United States law such as privacy, civil rights, and/or property law. This is not to say that human dignity is absent from the United States context, however it remains outside the realm of constitutional values unless it can potentially be drawn into the protections granted by the Constitution under the so-called penumbras of due process or other constitutional interpretations, such as was the case in *Roe v. Wade.*

The immediate result of these basic differences can be found in the very terms of the 1994 FBLs relative to assisted reproduction, human cloning, and embryonic stem cell research, whose numerous articles and clauses are distributed among the various French law codes (civil law code, public health law code, family law code, criminal law code, administrative law code, etc.). The laws – then and now – assure the integrity of the individual, forbid erosion of individual dignity, and guarantee respect for human life from its beginning, that is

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to say, conception.7 This does not conflict with France’s abortion law (Loi Veil) that allows for abortions up to the 12th week of gestation (increased from 10 to 12 weeks in 2001) on the sole basis of a woman expressing her situation as being one of “distress” (financial or psychological), or later-term abortions for medical reasons. Indeed, when a woman elects to terminate her pregnancy, her right to do so because of her expressed “distress outweighs the embryo or fetus’s right to respect for life from conception”.8

The French also decided that the human body is inviolable; its components can not be exploited for any reason, scientific or commercial.9 This emanates from the fact that in French law, respect for the human body constitutes an extra patrimonial right, in other words, though the body is not assimilated to the person itself, it is considered as belonging to the private sphere of that person. The body’s elements are not alienable objects, but rather represent the trace of the person they come from. Consequently, a person may not sell his/her body parts or gametes, nor may a woman serve as a surrogate mother, even without remuneration.10

Furthermore, assisted reproduction can only be undertaken as a treatment for a couple’s medically diagnosed infertility.11 Only heterosexual couples may apply and benefit from the state-financed medical treatment, and must be living together for at least two years and/or be married (no time limit).12 Single, lesbian, and post-menopausal women are denied access.13 Post-mortem insemination is forbidden.14 Artificial insemination with fresh donor sperm is prohibited.15 Sperm, egg, or embryo donation, providing it is not paid for, is lawful under specific circumstances, and only after obtaining the informed written consent of both the donor and receiver couple.16 The donor couple of an embryo must have already procreated, a man who donates sperm must also already have a child, while a woman donating an egg must both already have a child and be married or living with a man; a judicial authority must authorize all these type of donations.17 All donations must remain anonymous,18 and violation of the anonymity clause can result in a firm prison term and an elevated fine.19 Double gamete donations are prohibited, in other words, one of the couple’s members must be genetically related to the ensuing child.20 In 1994, all experiments on the embryo were forbidden, and embryos could not be created for experimental purposes.21 However, in exceptional circumstances, the man and the woman forming the couple could consent to studies on the embryo. Their decision had to be in writing, the studies had to have a medical purpose, and they could not harm the embryo.22 We will shortly see how this was expanded in 2004. As for preimplantatory diagnosis, it is allowed but only in very rare cases.23

10. “Les conventions ayant pour effet de conserver une valeur patrimoniale au corps humain, a ses elements ou a ses produits sont nulles”: art. 16–5 du Code civil.
11. In France, there were 797,400 births in 2004, all forms of conception combined: among these, approximately 45,000 IVF cycles a year; approximately 9,555 births per year from IVF; approximately 4,500 births per year by artificial insemination; approximately 80,000 amniocenteses per year for chromosomal diagnoses; approximately 600,000 blood tests per year to evaluate the risk of fetal chromosomal abnormalities; approximately 5,000 medical abortions per year linked to prenatal diagnoses, of which approximately 1,500 following a genetic abnormality detected following a biological analysis; approximately 100 pre-implantatory diagnoses per year, corresponding to 10–20 births. Source: Agence de la Biomédecine. http://www.agence–biomedecine.fr, accessed on September 12, 2005.
13. Ibid.
14. Ibid.
The role of the CCNE

What led to the French Parliament's passages of the FBLs in 1994? Undoubtedly, the top-down paradigm relative to regulatory procedures is highly pertinent, as indeed it all began with the role of the executive, President François Mitterrand, who through a presidential decree signed on February 23rd 1983 oversaw the creation of the CCNE (subsequently enacted in the law of 29th July 1994), placing France ahead as a pioneer in being the first country to have a permanent national consultative ethics committee. As reiterated in the August 6th 2004 law, the Committee's mission is to give opinions on ethical problems and social issues raised by progress in the fields of biology, medicine, and health.

This top-down model was then reinforced in the actual composition of the CCNE. It is now an independent authority and composed as follows: the CCNE President, nominated by the President of the Republic, an Honorary President, and 39 members. The CCNE President is nominated by decree by the President of the Republic for a period of two years that may be renewed.

The Committee is then composed of the following:

1° Five members designated by the President of the Republic, representative of the principal philosophies and religious faiths;

2° Nineteen members, chosen because of their qualifications, competence and their interest in ethical issues, as follows:
   * one member of the National Assembly and one member of the Senate, designated by the Presidents of these assemblies;
   * one member of the Conseil d'Etat, designated by its vice-president;
   * one member, a magistrate of the Cour de Cassation designated by its First President;
   * one member designated by the Prime Minister;
   * one member designated by the Minister for Justice;
   * two members designated by the Minister for Research;
   * one member designated by the Minister for Industry;
   * one member in the social sector designated by the Minister for Social Affairs;
   * one member in the education sector designated by the Minister for Education;
   * one member designated by the Minister for Labour;
   * four members in the health professions designated by the Minister for Health;
   * one member designated by the Minister for Communications;
   * one member designated by the Minister for Family Affairs;
   * one member designated by the Minister for Women's Rights;

3° Fifteen members engaged in research, i.e.:
   * one member of the Académie des Sciences, designated by its President;
   * one member of the Académie Nationale de Médecine, designated by its President;
   * a representative of the Collège de France, designated by its administrator;
   * a representative of the Institut Pasteur, designated by its director;
   * four research scientists, holders of a research post at the Institut National de la Santé et de la Recherche Médicale or at the Centre National de Recherche Scientifique, and two engineers, technicians, or administrative

officers at the Institut National de la Santé et de la Recherche Médicale or at the Centre National de Recherche Scientifique, and covered by the staff rules of those establishments, designated by half by the director general of the Institut National de la Santé et de La Recherche Médicale, and by half by the director general of the Centre National de Recherche Scientifique:

* two researcher–teachers or members of the teaching and hospital staff of the university and hospital centers on the electoral lists of the Institut National de la Santé et de la Recherche Médicale, designated by the director general of this institute;
* two researcher–teachers or members of the teaching and hospital staff of the hospital and university centers, designated by the Conference of university presidents;
* one researcher, holder of a research post at the Institut National de la Recherche Agronomique, designated by the president–director general of that establishment.

Members' mandates are fora duration of four years, and may be renewed once. Committee membership is renewed by halves every two years. The major deliberative organ of the CCNE is the Plenary Committee on which all members sit. Cases are studied by the Technical Section which is composed of twelve members designated by the whole Committee on the basis of the CCNE President's suggestions: four of them are from the group of members qualified by their competence regarding ethical matters, and the remaining eight are amongst those engaged in scientific research.

The CCNE is a purely consultative body, and it may be solicited by Presidents of Parliamentary Assemblies, members of the Government, higher education establishments, public institutions, or officially recognized foundations whose main activity is research, technological development, or the promotion and protection of health. But there is also the possibility of the Committee taking on matters raised by other persons than those listed above, or by one of its own members.

Each case is investigated by a working group, composed of members of the Committee who may request help from outside experts. The case is examined by the technical section who then decides on its examination by the Committee in plenary session. A final report is drafted and more often than not opinions and recommendations are made public.25

Meetings of the Committee and of its Technical Section are not open to the public. Secret ballot can be decided by the President or on request by one or several members present. Should the vote be equally divided, the President has a casting vote. The Committee and its Technical Section cannot deliberate unless at least half of its members are present.

This concentration of experts in their fields and the predominant role they played in the drafting of the 1994 FBLs was first analyzed by the French CNRS sociologist, Dominique Memmi, in the only book to my knowledge published in France on the CCNE,26 followed by an interesting study carried out by Julien Rocquet seven years later.27 Memmi clearly highlights the predominant position of the CCNE in the years prior to the drafting of the laws, while Rocquet, on the other hand, meticulously compares the totality of CCNE opinions to the actual phraseology of the 1994 law texts, demonstrating the proximity of words and language, consequently, the impact of the CCNE on the drafting of the laws.

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25. The Institut National de la Santé et de la Recherche Médicale (INSERM) (National Institute for Health and Medical Research) provides technical support to the Committee, in particular by making available for use a Centre de Documentation et d'Information sur les Problèmes d’Ethique dans le Domaine des Sciences de la Vie et de la Santé (Centre for Documentation and Information on Ethical problems in Health and Life Sciences).
The reliance of French legislators and Ministers on the CCNE and its experts in 1994 was easily understandable. Apart from a few, for example Jean-François Mattei (physician, deputy, and Health Minister from 2002 to June 2005) one may simply underline the lack of knowledge on the part of French Deputies and Senators relative to biomedical matters and their consequences, and of course the absence of mobilization on the part of their constituents, thus no need to respond and answer to them. In turn, this absence of mobilization was also easily explained by lack of public awareness. This configuration was soon going to change.

The Revised FBLs: from 1994 to 2005

In August 2004, the majority right–wing French Parliament passed the revised FBLs, following a five-year delay.28 Indeed, a clause in the 1994 texts stipulated that the law were to be revised in 1999. Several attempts to do so were accompanied by impassioned debate, first under the left–wing government of Lionel Jospin, then under the right–wing government of Jean–Pierre Raffarin, finally culminating in the new texts last year.

The major provisions of the new laws provide that reproductive cloning be defined as a crime against the human species and be subject to 20 years’ incarceration and a fine of 7.5 million Euros if carried out.29 This will also apply to French citizens who commit this crime in other countries. The law also bans therapeutic cloning and research on human embryos. However, by derogation and for a limited period of five years, it allows research on embryos conceived in vitro as part of assisted reproduction and on totipotent cells that may be generated as a result, provided this research is conducted on surplus frozen embryos no longer needed for procreation, and provided both members of the couple who created the embryo have given their explicit consent. The research must also focus on achieving major therapeutic advances that could not be obtained by alternate methods.30

The new laws also created a new institution, the Biomedical Agency (l’Agence de la Biomédecine) directed by Carine Camby, a graduate of l’ENA, France’s elite administrative graduate school. The Agency will authorize screening of IVF embryos that are selected to become “savoir siblings”, approve and oversee research on ESC, vet organ donations, assess embryonic research protocols, and generally enable government ministers to approve or reject new research. Under the Agency, French scientists can now draw on the country’s approximate 118,000 surplus embryos to create stem cell lines, provided that tightly controlled therapeutic and ethical criteria are met, and the couple whose gametes were used to create the embryo give their consent. Though not allowing for what is commonly called “therapeutic cloning” or somatic cell nuclear transfer, this improves the situation for French scientists who, since June 2004, were only allowed to work on a small number of imported ESC, and prior to that, on nothing at all.

From 1994–2005: Delays in revision amidst a changing socio–political landscape

Let us now turn to the parameters that first can explain the five–year delay in revising the 1994 FBLs and second point to a new dynamics in the French society. I will highlight several events and their relay by the media, the interaction between the latter and growing public awareness. Though the media began paying increasing attention to all events linked to so–called bioethics, the following were the most in view and gave way to the highest degree of growing awareness of public opinion and its expression.

29. Ibid, Titre VI, Articles 28 et 29.
30. Ibid, Titre VI.
First of all, quite naturally, one must cite the birth of Amandine, France’s first IVF baby in 1982, the result of René Frydman and Jacques Testart’s research team, which was to inspire reactions more of awe than any criticism relative to the advent of IVF in France. This was to last up to the publication of Jacques Testart’s book, *L’œuf transparent*, and the highly mediatized stance he took following Amandine’s birth in denouncing the “Taylorization of procreation” and evoking the specter of “democratic eugenics”. This was going to instill initial doubts relative to assisted reproduction, first in smaller intellectual circles, then spreading both in the media and public opinion polls. The media, in paying more attention now to these issues, was going to maximize coverage of the following events, influencing to a large extent public opinion and that of decision-makers.

Undoubtedly, the contaminated blood scandal was a major factor contributing to a sea change in the French society. From 1983 to 1985, the National Center for Blood Transfusion (CNTS) - the public company that collects and processes blood supplies - distributed stocks of non–treated blood that they knew to be contaminated by the HIV virus. More than 4,000 victims received these poisoned transfusions, mostly in the French hemophiliac population. Many of them have since died. Judicial proceedings against the Ministers of the Socialist government under Laurent Fabius – Fabius himself, Georgina Dufoix (Minister of Social Affairs), and Edmond Hervé (Health Minister) continued until the end of the 1990s, and in 1992–1993 the High Court of Justice dropped the charges against the Ministers for lack of evidence. One last attempt by the French Hemophaeic Association to obtain a condemnation failed, but Dr. Jean-Michel Garretta, head of the CNTS in 1985, was condemned to four years of prison.

The contaminated blood scandal (and to a certain extent, coverage of the Mad Cow disease and its evolution), was probably going to contribute more than any other event to both an increasing loss of confidence in politicians on the part of the French, as well as a transformation in the traditionally paternalistic relationship between doctor and patient, leading the French to assemble in issue–based associations and/or seek out information on their own. Indeed, many of the latter emerged in the late 1980s and early 1990s, certain focusing on patient rights, others devoted to assisted reproduction and/or patients rights and access in this domain ; for example, *Pauline et Adrien*31 (the equivalent of the US association RESOLVE), the Association *Maïa*32 aiding couples, among other things, to find surrogate mothers abroad, and the French Association of Gay and Lesbian Parents and Prospective Parents,33 created in 1986 and very active during the debates in the French Parliament concerning the PACS, a law passed in 1999 allowing civil union contracts for both hetero and homosexual couples.

Indeed, one of the reasons why the 1994 FBLs laws were not revised in 1999 has to do with the PACs law and debates prior to its passage. One of the hopes of the Gay and Lesbian Association, relayed by certain Communist or Green Party representatives within the National Assembly was that the PACs would not only allow for same–sex unions, but also open adoption and/or access to assisted reproduction for homosexuals. One of the arguments put forth was that single women have the possibility to adopt, but not lesbian women, and that this paradox led to many single lesbian women to adopt simply by lying about their sexual orientation. In addition, the Association argued, there was no coherent psychological and/or philosophical argument that justified allowing single women to adopt and not stable homosexual couples.

Debate in Parliament about this aspect, and about the PACs in general, revealed the existence of engrained homophobia among some Deputies, both Left and Right–wing alike, relayed by the press’s insistence on comments about the “abnormal nature of homosexuality and the even more abnormal prospect of homoparentality”.34 Seeing that the Gay and Lesbian front was ready to be a vocal part of revising the FBLs by

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31. [http://www.paulineadrien.com](http://www.paulineadrien.com)
32. [http://www.maia-asso.org](http://www.maia-asso.org)
34. According to recent studies, 11% of homosexual French women and 7 % of French men are raising children ; it is estimated that there is between 4–6% of homosexuals in France, hence this translates to several
fighting for access to assisted reproduction, the Socialist government under Lionel Jospin decided to put off the revision until after the presidential elections set for 2002. They never got around to that as we all know what happened in April 2002; Jean–Marie Le Pen beat Lionel Jospin in the first round of the Presidential elections.

The third major event that contributed to shaping public opinion and that of legislators was the announcement of the cloning of Dolly in February 1997. As we all know, President Jacques Chirac’s fervent appeal for international legislation banning human reproductive cloning would join that of President Clinton’s and contribute to a growing climate of apprehension when faced with the potential of new techniques. Indeed, the leitmotiv, “the specter of eugenics”, was going to permeate another highly mediatized event, the Nicolas Perruche affair.

The Perruche affair was erroneously presented as France’s first (and last) wrongful life case and led to a law putting an end to the Cour de Cassation’s decision in November 2000 to award significant damages to Nicolas Perruche, born with the Gregg syndrome, following an error in diagnosing the presence of Rubella in the mother during her first trimester of pregnancy. The laboratory that had taken her blood sample had determined that she had not contracted the German measles from her 4–year–old daughter, and could pursue her pregnancy without a qualm. She had previously indicated to her doctor that if she had contracted Rubella, she would have an abortion. In fact, she had contracted Rubella, and the Court awarded damages not only to the parents but to Nicolas.

The ensuing reaction and debate was ferocious, and revolved around whether Nicolas could also be defined as a plaintiff, the victim of having a “wrongful life” imposed on him. For most, such a request was both unprecedented and inapplicable, however the Court underlined that their decision was not motivated by the concept of “wrongful birth/life” but rather by the fact that Nicolas Perruche’s severe handicaps were in a “direct causal relationship with the diagnosis error”. This reasoning did not appease the vast array of commentators, doctors, sonogram specialists, lab technicians, bioethicists, jurists, philosophers who generally denounced the “horrific advent of eugenics in France” through the Court’s decision and “condemned the court for opening the way towards abortion on demand at the slightest sign of fetal abnormality”. Those who pronounced themselves with a more ambivalent position were associations regrouping parents of handicapped children: on the one hand, the decision was considered a welcome one for it provided financial means to care for such a severely handicapped child, yet on the other hand, they also felt that the decision diminished the value of the lives of these very children.

The most important mobilization came from the medical community itself, especially obstetricians, gynecologists, and sonogram specialists who, beginning to drown under heavier insurance premiums, seized upon the issue to press the Parliament to pass a law prohibiting a person to file suit for “wrongful life”. At first, most of the leading Socialists were reluctant to pronounce themselves in public, and in private said they had no qualms with the Court’s decision. But under increasing media coverage and debate and pressure from the medical community, all maximizing the eugenics theme, in a knee–jerk reaction, the Socialist majority and the rest of Parliament passed a law in 2002 virtually outlawing the type of litigation that Perruche represented.

thousands of children being raised by French homosexuals or couples. See a complete report at http://homoparentalite.free.fr.

35. Forgive me for the anecdote, but in September of that year, there was a two–fold increase in the number of students signing up for my optional class, Bioethics and the Law, that I teach at the University of Paris Law School, and the reason given when I asked them why they signed up was the fear of human reproductive cloning and, once again, the “specter of eugenics”.


38. Loi n° 2002–303 du 4 mars relative aux droits des maladies et à la qualité du système de santé.
Last but not least, the Vincent Humbert affair must be mentioned. Vincent Humbert, tetraplegic following a car accident in September 2000, wrote a letter to President Chirac in December 2002 asking to benefit from the “right to die”, a request that would of course not be granted. A year later on September 24th 2003 his mother, Marie Humbert, administered a lethal injection to her son (in hospital) and the attempt failed. He entered into a profound coma, Marie Humbert was arrested, and his attending physician Dr. Chaussoy, in accordance with a medical group decision, ceased to procure reanimation care to Vincent Humbert who died on September 26th. Both Marie Humbert and Dr. Chaussoy were then charged and are awaiting their trial, but are free. Marie Humbert has become the emblematic figure of the Association for the Right to Die with Dignity.

Finally, the image of what goes on in the US has also played an important role. These particular events in France, significantly relayed by the media, constantly meshed with media portrayals of similar events in the United States, and provoked the seeming necessity for both specialists and the public at large to take a stand. In either a willful attempt to play on the relative ignorance of the French public by systematically portraying events in the United States in a negative light (the “Wild West” of assisted reproduction where anything goes), or the significant lack of knowledge on the part of the media (even the prestigious Le Monde sometimes gets it wrong) of how the United States functions, its important reliance on the concept of privacy in matters of procreation, how federalism functions, the fact that regulations do exist, all has resulted in facing a Manichean choice; one is either pro or anti-American. Hence an association like the Association for the Right to Die, Maia, or the Gay and Lesbian Association will emphasize the importance individual autonomy, and thus rely more frequently on concepts such as privacy and choice, and thus be perceived of as pro-American. On the other hand, those who stigmatize the United States context and seek to emphasize the human rights framework that seemingly protects the general interest feel forced to minimize the exclusion of certain categories of the population, such as homosexual couples.

Hence, in the area of assisted reproduction for example, this has led to a growing phenomenon known as “reproductive tourism”, illustrated, among other examples, by the fact that 90% of all artificial insemination requests at St. Pierre Hospital in Brussels come from French lesbian couples, or the fact that a Danish entrepreneur has just announced that he will launch a “fertility ship” where persons or couples who live in restrictive European countries can have access to assisted reproductive techniques their countries ban. This is an inevitable result in countries with far too stringent laws, according to the provocative analysis of the bioethicist, Guido Pennings.

Conclusion

In this contemporary changing French environment which now witnesses the increasing role and importance of interest groups, yet another interest group has decided to join the fray, not necessarily with regards to the FBL, but in trying to impact public policy in the realm of research. With the launching of their movement Sauvons la recherche in 2003, the French scientific community (a majority of “hard scientists” but also social scientists), have mobilized. In a cross-partisan gesture in March 2004, more than 2000 laboratory directors and research unit directors signed in protest against the general woeful status of the French university and its research units as well as Raffarin’s right-wing government’s lack of financing and creation of research

39. http://www.admd.net. A well-known member of this association, Mireille Jospin–Dandieu (Lionel Jospin’s mother), exercised her right to die with dignity last year.
positions. Their movement has generated a great deal of sympathy on the part of the French public, and thusfar it has been partially successful.

Some participants in this movement, which still exists and is vigilantily supervising the government are also involved in the ESC issue and have mobilized in light of the fact that more than a year after the FBLs were passed, many of the articles within have not received the appropriate administrative injunction allowing for their application. Under the impetus of increasingly outspoken voices from the scientific community and patient interest groups, an important report was submitted before the National Assembly by the Deputy, Pierre-Louis Fagniez (surgeon, UMP, right-wing political party) on March 23, 2005 denouncing these delays, and pinpointing the reasons for them. The report underlined that the laws to be applied, 47 administrative texts had to be signed and thusfar only a miserable 3 (4% of them) had been signed.\(^4\) The report blamed priority given by the National Assembly to the bill relative to health insurance reform, but moreso the complexity and weight of administrative approvals and procedures just to get the administrative texts signed. For example, simply finalizing the creation of the Biomedical Agency requires a decree by the Conseil d'Etat, who in turn has to receive approval beforehand from almost a dozen different organisms.\(^4\)

Another reason given by the report underlined the endless interministerial meetings that must be held to agree upon the wording of the various administrative application texts, as well as coordinate their wording with European norms (for example the European Directive n° 2004/23/CE of the European Parliament and Council of March 31, 2004 relative to the establishment of quality and safety norms for the donation, retention, control, transformation, stock, and distribution of human tissue and cells).\(^5\) Last but not least, Fagniez's report underlined a simple economic explanation: two of the most important departments responsible for drafting the administrative texts, the Social Security Direction (DSS, Direction de la sécurité sociale) and the General Health Direction Service (DGS, Direction générale de la santé), simply do not have the human and material resources to handle the workload.\(^6\) The report's conclusion criticized the government for its poor organization and delays, and called for urgent rapid action for "patients, families, health professionals, and researchers who are impatiently awaiting their application".\(^4\)

At this very moment, several application texts are in the process of being signed and will allow the following parts of the 2004 laws to go into effect: required conditions for examining genetic characteristics; Article 12, relative to cellular therapy; Article 23, relative to prenatal diagnoses and PID practices; Article 24 relative to assisted reproduction and to gamete donations; Article 25 relative to research on embryos and embryonic cells.

Meanwhile, the delays the Biomedical Agency is experiencing in signing the administrative text\(^7\) must handle has spun off into another issue with a formal petition signed by ten leading French scientists presented to the French Parliament in July 2005 calling for the legalization of somatic cell nuclear transfer. Among those who have signed, two former Nobel recipients, Professors Jean Dausset and François Jacob, as well as four members of the Academy of Sciences, Etienne–Emile Beaulieu (the creator of the RU 486, or "abortion pill"), Alain Fischer, François Gros, Nicole Le Douarin, and Professors René Frydman (the "father" of France's first IVF baby), Marc Pechanski (INSERM), Ketty Schwartz (CNRS), and Claude Sureau (President of the National Academy of Medicine).

This is one example among many of how certain branches of France's civil society are organizing and seeking to exert influence on public policy relative to biomedical practices and their consequence. Though the CCNE still plays an important role, it remains a consultative organ, and one that is not indispensable. To


\(^{4}\) Ibid, p. 11.

\(^{4}\) Ibid., p. 12.

\(^{4}\) Ibid.

\(^{4}\) Ibid, p. 17.
illustrate this, one example comes to mind. During Nicolas Sarkozy's first mandate as Interior Minister (Ministre de l'intérieur, de la sécurité intérieure et des libertés locales – 07/05/2002) he sponsored a security law which was passed in 2003 that allows for the genetic info of suspects to be collected: this type of law would have previously been the opportunity for a Prime Minister to seize the CCNE and request a guiding opinion, something Nicolas Sarkozy did not do.

Hence, with the CCNE settling more comfortably into its role as a purely consultative organism, and the growth and emergence of the civil society, especially grass-roots and interest groups, France has now firmly placed both feet into the modernity of biomedical practices and their consequences. Chances are that this new-found role of France's civil society in bioethical issues will soon play an even more important part in the shaping of future law revisions; what was once a process bringing experts to legislation might soon become one of bringing public debate to legislation, something we can certainly hope for.