



Ségolène Aymé, Paris

## Genoa Meeting

May 17, 1997

Ladies and Gentlemen,  
Dear Colleagues and Friends,

I would like to welcome you all to this 29th Annual Meeting of the European Society of Human Genetics (ESHG).

Thanks to the highly diverse cultural background of European countries, every meeting has its special flavour. This 1997 meeting is held in a city which has produced many famous discoverers and adventurers. I leave it up to you to decide in which category our host, Professor Giovanni Romeo, falls, but obviously he is from the same lineage as all the famous sons of Genoa. He was the initiator of the second birth of our society, and the founder of our journal, which, despite its recent creation, already has an impact factor of 3.2 thanks to the inspiring style of its first editor-in-chief.

The ESHG has 1,200 members from 60 countries. More than 10% of the members originate from Eastern European countries. All these countries differ in their culture, their sociology, their economics, and somehow their only common language is the language of Science. We are all excited by the same discoveries and we all work in the same directions, which explains that major steps forward are always made by several independent teams almost at the same time.

The front line of research is international, but the applications are quite dependent on the perception of the community, on the structure of the health care systems, industry and of course on the economy of each country.

I urge you to read two special issues of the *European Journal of Human Genetics*, one already published and one to appear soon, on prenatal diagnosis and genetic services in Europe. You will discover the diversity of practices and policies, the differences in the introduction of new technologies, not explainable by economic reasons, but truly by a different cultural approach.

The official goal of our society is to promote research in basic and applied human medical genetics. Does research need promotion? It seems to be going strong. In fact, research in genetics has been so active over the last years that the gap between spectacular discoveries supposed to help us understand the role of genes and their use for practical purposes is creating a new source of tension between the public and the scientists.

We are regarded with suspicion: are we just playing games, dangerous games at that? Or are we helping to improve the public welfare? The cloning of Dolly, while certainly a landmark event, was also a negative event in my opinion. Indeed I was not satisfied by most of the arguments advanced to declare that cloning was an unacceptable type of research. Few people seem to fight against cloning animals, as the artificial selection of species is a very old and well-established practice. But everybody is horrified by the idea of a human clone, whatever the model – Saddam Hussein or Catherine Deneuve – and when scientists speak up against human cloning, very few give any good reasons. They usually say that not all experiments in animals can be done in humans, that it is hardly feasible, and that it is not essentially different from monozygotic twinning. Usually, they forget to say that what is

shocking is that, whereas all we represent in the world is defined by our place in the society we belong to, a product of cloning will have no parents or relatives; such a person will neither be the child nor the sib of the model. What we dislike is the fact that he/she will not fit into our model of society, where the family is still the model of social organisation. For how much longer? We need to talk to each other to deeply explore all these concepts and try and solve the tensions which may arise.

As I said, another source of tension is the gap between discoveries and their applications. To fill this gap, we should work more closely with industry and consider its representatives as natural partners. The ESHG has established a real partnership with a few companies in the hope of creating a climate of mutual understanding and an active collaboration towards the creation of services of the highest technical, moral and ethical quality. We share the same concerns. We have common interests, but we should all keep our independence.

One of the dangers in the coming years, with the shortage in governmental funding in most countries, is to have research entirely money driven. At the European Union level, the danger is real. Where is the room for biomedical philanthropy and where is the room for pharmaceutical industry titans? The economic tensions within and between countries are such that there is a need to redefine the goals of research. The best way to reach a consensus is again to talk to each other, we the scientists with our industrial partners and with the lay-association representatives.

Our partnership with the latter is now well established. The role of patient organisations in the development of research programmes has been major in these last years, not only because of their capacity to raise funds, but also because of their determination to share their choices and their priorities with us. As scientists, we have responsibilities which have been well defined by the Council of Regional Networks Committee on Ethics. We have responsibilities towards patients and their families. We should serve them with equity and respect for each person's feelings, beliefs, traditions and social circumstances; this is no easy matter. The ESHG decided to organise a session dedicated to psycho-social issues in genetics and to public awareness in general at each annual meeting. Genzyme Genetics has kindly offered to sponsor it. We definitely also have responsibilities towards the community at large. We should provide assistance in the understanding of genetics and participate in the establishment of appropriate regulations of genetic services. We should aim at achieving an appropriate balance between the

rights of individuals and the needs of Public Health. This may prove very difficult, either because of economic constraints which could be overprioritized or because human rights are not yet established as a principle everywhere or understood uniformly. The scientific community has recently expressed deep concern about the Chinese eugenics law which promotes pre-marital selection, and many scientists strongly criticized this law as an abuse of genetic information and a violation of human rights. Jointly with the European Alliance of Genetic Support Groups, the ESHG published a statement in August 1995. It was a formal complaint against the Chinese Government, as this law is in conflict with the Declaration of Human Rights, article 16, which says that men and women of full age, without limitation due to race, nationality or religion, have the right to marry and found a family.

After us, some prominent leaders in the field of medical genetics are now calling for a complete boycott of scientific collaboration, training of postdocs and any meeting organized in China.

Next year, the International Congress of Genetics is scheduled in Beijing and many colleagues want to boycott it. Would it not be more useful to organise excellent meetings in China to help non-scientific communities to distinguish between modern science and pseudo-science?

Let us not forget that we have a bitter historical experience with a negative eugenic policy in Europe, a policy that was widespread until the middle of this century, and was still being conducted in several countries until the seventies. Of course, we should publicly protest against a law like the Chinese one, but at the same time we should keep up the dialogue with our colleagues who are advising their government and who are training the young generation. Let us not forget either that there is no international agreement on a wide range of medical issues, even among Western nations. It is even more difficult to reach such a consensus at the international level.

In October 1996, the International Federation of Human Genetics Societies was created to provide a forum for organised groups, dedicated to all aspects of human genetics. The federation aims at developing a consensus on policy matters of international concern. It will promote meetings, publications and other forums which support human genetics research and practice.

The first item of its agenda is to contribute to the revision of the guidelines on ethical issues in medical genetics and the provision of genetic services, issued by the WHO in 1995.

We also have a responsibility towards the profession which aims at establishing and maintaining professional

competence, sharing expertise, and encouraging one another in ethical conduct. One example of the Society's activity in this field is the establishment of quality guidelines and standards for genetic services. Recently, the Eucromic concerted action produced very interesting guidelines for genetic laboratories and clinics on prenatal diagnosis from fetal biopsies obtained by invasive procedures. These guidelines are open for discussion within the society on our web site. Please comment on them. Another

example is the organisation of forums like the one we will have late tomorrow afternoon on the peer review system in Europe, a very hot, very rarely addressed topic. Finally, the ESHG aims at promoting research.

We expect three full days of exciting scientific sessions. They are dedicated to our youngest colleagues in this audience who are attending an international meeting for the first time. Enjoy your meeting, enjoy your colleagues, enjoy your life.

## Announcement

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The proceedings of the European Society of Human Genetics (ESHG) congress held in Genoa, Italy, on May 17–20, 1997 have now appeared in volume 2 of *Medizinische Genetik*, volume '97. The selected abstracts can now be referenced as published in *Medizinische Genetik*.

The ESHG thanks the editor-in-chief, Christine Scholtz, and the head of the editorial board, Prof. Murken, for having accepted to offer a full issue of their journal for the publication of the proceedings.