European Commission
Community Research

# genetics and the future of Europe

A dialogue of European dimension



# GENETICS AND THE FUTURE OF EUROPE

**• Almost daily the media announce new advances in genetics. Yet only 13% of European citizens feel adequately informed on biotechnology. This is one of the lessons of the fourth Eurobarometer survey on *'The Europeans and Biotechnology'*, published in April 2000. Even more alarming than the perceived lack of information are the growing doubts as to how reliable the available information really is. In answer to the question *"Which source(s) of information on biotechnology do you trust?"*, consumer associations and doctors scored highest, with 55% and 53% of Europeans saying they trust these sources. Scientists and public authorities enjoy the trust of only 25% and 15%, respectively.**

**• It is necessary to ponder these figures. Europeans feel confused about advances in genetics research. Certainly, the power that comes with increasing knowledge of life opens new horizons, new prospects for improving the quality of life. Medically assisted procreation is already a major step for mankind, but it does raise issues. The new therapies and medicines stemming from discoveries in genomics may lead to undreamed of progress in human health. Yet when it comes to genetically engineering animals and plants, many people tend to question or reject new advances immediately. These fears and expectations are widening the gap between the public and research in biotechnology.**

**• In today's society, the debate on these issues is highly sensitive. Scientists at the cutting edge of progress in life science – as well as the political and economic decision-makers who have to endorse the choices of new applications – need new forums for pursuing a dialogue with society, a dialogue open to all. This pluralism should enrich the debate for everyone. In this spirit, on 26 April 2000, Research Commissioner Philippe Busquin launched a Life Sciences High Level Group composed of 11 European biologists. The members of this group are recognised for their scientific excellence, their involvement in the debate with society, and their commitment to communicating with the public on the stakes for research in genetics. One task of these experts is to inform the Commissioner on the prospects for life sciences research. Another is to formulate proposals for a better dialogue between scientists and society. The discussion forum on Genetics and the Future of Europe, held in Brussels on 6 and 7 November 2000, is the first concrete result of this initiative.**

# European dialogue bears fruit

COMMISSIONER PHILIPPE BUSQUIN

*"The variety of expertise and the wide range of opinions that converge here prove that there is nothing conventional about this debate."*

**Pluralism was of the essence at the forum on Genetics and the Future of Europe, held in Brussels on 6 and 7 November 2000. The meeting marked the kick-off of a new dialogue between life scientists and representatives of civil society in the European Research Area. Here are the ideas that animated this pioneering debate.**

• *"The variety of expertise and the wide range of opinions that converge here prove that there is nothing conventional about this debate,"* stressed Commissioner Philippe Busquin as he addressed the assembly of nearly 300 participants. Over half of these were members of civil society, representing a wide range of its components - patients' associations, environmental protection groups, religious organisations, and human rights movements. In dialogue with them were people directly involved in the development of genetics: European and national politicians, scientists, doctors, lawyers, and representatives of the biotechnology industry.

• As there was no dominant majority, the debate was lively and penetrating over the two days of the forum, never descending into sterile confrontations. The pluralism of the assembly enriched the discussions, which were conducted in a climate of mutual respect acclaimed by all participants.

• *"Genetics has a past, it is the present, and it's up to us to invent its future!"* exclaimed Axel Kahn, President of the Life Sciences High Level Group. The plenary sessions centred on this "inventing". Focusing on four major themes, they probed deep into the concerns that genetics arouses in the areas of human health, food and agriculture, environmental protection and biodiversity, and the responsible use of genetics[1].

(1) The first three sessions were chaired respectively by three members of the High Level Group: Professors Winnacker (DE), Van Montagu (BE), and de Lorenzo (ES). The chairman of the fourth session was Professor Quintana-Trias (ES), vice-president of the European Group on Ethics in Science and Technology.

# genetics and the future of Europe

## Mixed feelings

◗ Today, Europeans feel out of their depth when it comes to genetics research. All genetics? Certainly not. When molecular genetics provides tools to serve the environment – such as tools for eliminating pollution – it receives widespread support. This shows that the public can understand that *"micro-organismes are our friends: they are smarter, wiser and more energetic than chemists and engineers"*[1]. *"We have to make them aware of the extraordinary microbial diversity of the biosphere, where the bulk of unknown life forms enzymes and bioactive molecules are awaiting us to be discovered and applied for human benefit."*[2]

◗ Medical genetics elicits a more ambiguous response: on the one hand shines the hope of fighting certain diseases, while on the other hand looms the "spectre of eugenics"[3]. Yet European opinion is above all hostile to crop genetics, and especially to genetically modified organisms (GMOs) in foods. This mistrust is not totally rational: *"When people refuse chocolate because the label mentions an infinitesimal GMO content, do they even think twice about the risk that traditional chocolate might contain extremely dangerous mycotoxins?"*[4] Yet it is not totally irrational, either: "Let us acknowledge that currently a purely scientific risk assessment is impossible."[5]

◗ Europe will not be able to exploit fully the promise of genetic engineering unless it succeeds in dealing with these concerns and manages to integrate them into a coherent whole, despite their somewhat contradictory nature.

(1) ENRICA GALLI, UNIVERSITÀ DEGLI STUDI, MILANO (IT)

(2) VICTOR DE LORENZO, CENTRO NACIONAL DE BIOTECNOLOGIA (ES).

(3) ERNST–LUDWIG WINNACKER, DEUTSCHE FORSCHUNGSGEMEINSCHAFT, (DE)

(4) JAROSLAV DROBICK, BIOTREND ASSOCIATION (CZ)

(5) SUE MAYER, GENEWATCH, BUXTON, (UK)

MATT RIDLEY

*"In Britain, 90% of the population say they no longer trust official announcements on scientific matters."*

ENRICA GALLI

*"Micro-organismes are our friends: they are smarter, wiser and more energetic than chemists and engineers."*

## The need for a common dialogue

◗ Scientists have thus partially lost the public's trust, and public authorities are not spared: *"In Britain, 90% of the population say they no longer trust official announcements on scientific matters."*[1] The management of the mad cow crisis and the difficulty with which public authorities have been able to respond to it have left their marks.

◗ How can a dialogue be renewed with a public disenchanted by the lack of sound scientific basis in day-by-day decision-making? Might the current mistrust be an opportunity to establish a new link, based on a common need for dialogue and an attentive ear? *"As a scientist, I do not expect society to trust me, but to pay attention to my warnings."*[2]

◗ Innovative experiences exist in this area, such as the involvement of Swiss scientists in the 1998 referendum on banning genetic engineering. Forced to explain publicly the meaning and value of their research, they learned much from jumping into the arena of public debate. *"Difficult scientific notions are now a part of everyday vocabulary. Society as a whole has been truly enriched by this debate."*[3]

(1) MATT RIDLEY, THE INTERNATIONAL CENTRE FOR LIFE SCIENCE (UK)

(2) AXEL KAHN, INSTITUT COCHIN DE GÉNÉTIQUE MOLÉCULAIRE (FR)

(3) ROLF ZINKERNAGEL, UNIVERSITY OF ZURICH (CH).

# genetics and the future of Europe

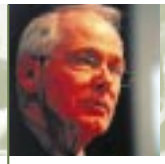
## New missions for scientists

◗ *Science must "stop functioning as a club, with its rites and jargon"*(1). The scientific profession thus gains a new – currently neglected – social function: the "duty to communicate."(2) Initiatives in this direction have emerged: *"Starting next year, our postdoctoral fellows will receive training in how to communicate their scientific knowledge."*(3)

◗ Scientists must learn to respect and understand public expectations and responses. Food, for instance, embodies many cultural values, and in the eyes of some, GMOs pose a threat to those values. *"The consumer does not have to justify what he wants to eat."*(4)

◗ It is not up to public opinion, however, to dictate to scientists the orientations of their research – freedom of research is included in the European Charter of Fundamental Rights. What is necessary is to develop participative methods enabling society to become involved in research policy decisions. As for the applications of this research, they must clearly be the subject of a thoughtful dialogue. *"Society must increasingly answer questions based on highly complex scientific issues"*(5), and it is the imperative mission of scientists to contribute objective elements to the debate.

(1) EGBERT SCHROTEN, UNIVERSITY OF UTRECHT (NL)
(2) RENÉ FRYDMAN, HÔPITAL ANTOINE BECLÈRE (FR)
(3) FRANK GANNON, EUROPEAN MOLECULAR BIOLOGY ORGANISATION
(4) WOLF-MICHAEL CATENHUSEN, BUNDESMINISTERIUM FÜR BILDUNG UND FORSCHUNG (DE)
(5) AXEL KAHN (FR)


EGBERT SCHROTEN

*Science must "stop functioning as a club, with its rites and jargon"*


FRANCK MULCAHY

*"We have accumulated life experience, concrete knowledge that we want to confront with the knowledge of scientists".*

## Patients' expectations

◗ Health is a typical example of an area where dialogue and transparency are indispensable. The patients' associations present at the forum expressed forcefully the wish to be more closely associated with biomedical choices, since they are *"directly concerned by biomedical research applications"*(1). What can they contribute? *"We have accumulated life experience, concrete knowledge that we want to confront with the knowledge of scientists."*(2)

◗ Some participants, on the other hand, expressed the fear that biomedical research applications will lead to genetic discrimination against patients. Safety barriers must be erected. *"We are pleased that non-discrimination against disabled persons has been included in the European Charter."*(3)

◗ For others, *"the suffering of patients is such that we cannot afford to agonise endlessly over decisions"*(4). For example, pre-implantation diagnosis has already enabled people suffering from monogenic diseases to conceive healthy children – something nobody even dared to dream of 15 years ago.

(1) BERNIE MORAN, HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
(2) FRANK MULCAHY, EUROPEAN DISABILITY FORUM (IR)
(3) HENRI FAIVRE, ASSOCIATION DES PARALYSÉS DE FRANCE
(4) ALASTAIR KENT, GENETIC INTEREST GROUP (UK)

# genetics and the future of Europe

## The basis for a pluralistic ethical debate

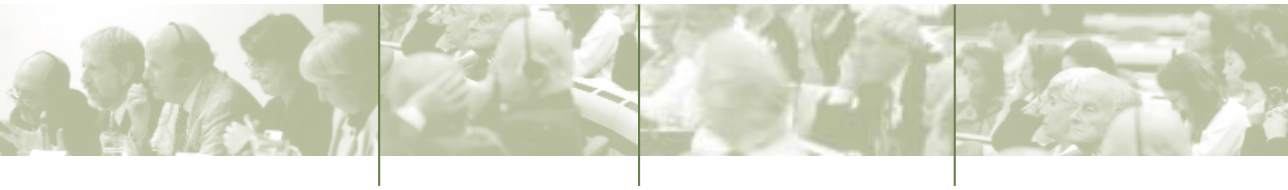
Pluralism can enrich any debate, but could there be a risk that our diversity of sensitivities, of national and regional cultures, might preclude even minimal European agreement on a basic set of ethical principles? Geographic boundaries are not necessarily the determining factor: *"The diversity of ethical values and beliefs is often greater within each Member State than between states of the Union."*(1) This means we must build on a consensus based on *"a foundation of common European values"*(2) such as democracy, human rights, solidarity, and sharing. *"Finally, all of us are equally affected by the genetic risk."*(3)

It is also important to define clearly the role and usefulness of ethics committees. *"The mission of these committees is not to give a functional answer to the questions asked, but rather to progress gradually towards a consensus on the nature of the stakes."*(1) In reality, *"the ethical debate always depends on the context and always proposes several, equally valid solutions to a problem."*(3)

(1) OCTAVI QUINTANA-TRIAS, INSALUD (ES) (2) AXEL KAHN (FR)
(3) DAVID MCCONNELL, TRINITY COLLEGE DUBLIN (IR)

## The role of industrial research

Some participants asserted that dynamic industrial research is a key driving force for progress in the life sciences and for translating this progress into tangible benefits. *"Profit motivation is an effective incentive that should not be looked down upon, but encouraged."*(1) *"We should worry, instead, about Europe lagging behind the USA in the biotechnology sector."*(2)



Others, however, fear that industry's profit motive will be an obstacle to carrying out global priorities, as attested by *"the poor state of research on infectious diseases or livestock pathologies prevalent in tropical countries"*(3). Lastly, *"Might private interests and the lack of transparency regarding technology choices be a cause of citizens' mistrust of biological research?"*(4)

(1) JOHN MARTIN, UNIVERSITY COLLEGE LONDON (UK)
(2) JOHN PURVIS, MEMBER OF THE EUROPEAN PARLIAMENT
(3) PATRICK CUNNINGHAM, TRINITY COLLEGE DUBLIN (IR)
(4) ELS TORREELE, VRIJE UNIVERSITEIT BRUSSEL (BE)

## Patenting life

Directive 98/44 on the protection of biotechnological inventions, currently being transposed into national legislation in the Member States, stipulates that the discovery of a human genome sequence cannot be patented, but rather that a biotechnological process that utilises that sequence with a view to specific applications is patentable.

Does the wording of the directive leave the door open to misinterpretations? *"Should someone who has discovered a gene for one particular function, and is able to produce it by biotechnology, own that gene, for the next 20 years, for functions that have not yet been discovered?"*(1) Some participants expressed the view that it is necessary to clarify how this essential directive is to be applied.

(1) ERNST-LUDWIG WINNACKER, UNIVERSITY OF MUNICH (DE)

genetics and the future of Europe

## Of media and mediators

◗ The dialogue between science and society requires mediators capable of organising an open and constructive debate. The work of journalists is sometimes criticised. *"The media tend to silence the moderate middle and polarise the debate."*(1) New settings for mediation must be invented, such as the International Centre for Life Science (UK), which associates life science training, research, economic valorisation, ethical reflection and popularisation, all at the same site.

◗ The major scientific institutions and parliamentary offices are becoming increasingly involved in the debate. Other organisations, such as *"engineering academies and the European Social and Economic Committee, should do the same"*(2).

◗ An effort must be made to give health professionals training that will enable them to advise and inform their patients. New counselling professions may emerge at the intersection of science popularisation, public education, and reflection within society.

◗ The Danish experience of *"consensus conferences" was also applauded. "Why not take initiatives like this at the level of the European Parliament or provide EU funding to organise such conferences throughout Europe?"*(4)

◗ Today we enjoy the privilege of the fabulous tools that information technology has made available. We can exploit them to develop a dialogue. At the end of the Forum, Commissioner Busquin himself inaugurated this approach by holding a two-hour Internet chat with dozens of citizens of all nationalities, who had been invited to ask questions and give their opinions on *"genetics and the future of Europe"*.

(1) MATT RIDLEY (UK) (2) ALAIN POMPIDOU, MEMBER OF THE EUROPEAN PARLIAMENT (FR)
(3) PHILIP CAMPBELL, NATURE (UK) (4) LORD KENNET, MEMBER OF THE BRITISH HOUSE OF LORDS (UK)

OCTAVI QUINTANA-TRIAS

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ELS TORREELE

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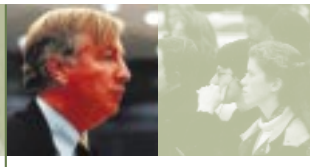


JOHN MARTIN

*"Profit motivation is an effective incentive that should not be looked down upon, but encouraged."*

## Projects for a new European dialogue

◗ *"The dialogue between science and society must enter into the making of science policy. This requirement is clearly stated in the discussion document that the Commission has just submitted as part of the establishment of the European Research Area. ERA must stimulate measures to encourage such a dialogue, with special emphasis on the new practices and experiences that are yet to emerge."* In his closing speech, Commissioner Busquin thus invited all geneticists and biologists to make 2001 the start of a new process of exchange and reflection with society.

◗ With this goal in mind, on 15 November 2000 the EU launched a call for proposals for projects promoting the innovative communication of advances in biology, citizen participation in scientific deliberations, and closer co-operation between regions, countries, and institutions.

◗ The Brussels forum has shown that sharing the know-how gained in many small local initiatives can be a very effective tool for progress in the dialogue between science and society.

## The Life Sciences High Level Group...

Over the past decades the life sciences have made tremendous strides, with major potential benefits for human health, the environment, and European industry. The almost complete sequencing of the human genome is an example of this. At the same time, applications of the new knowledge raise ethical and safety concerns among the public and policy-makers that must be addressed.

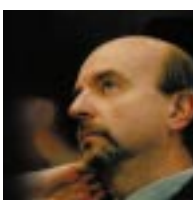
The Life Sciences High Level Group (LSHLG) was established in April 2000 by the Research Commissioner Philippe Busquin to meet his need for high-level advice on the life sciences and technologies. One of the group's tasks is to inform the Research Commissioner on the current situation in this field and on imminent or foreseeable developments. Another duty is to contribute to the organisation and animation of a Life Sciences Discussion Platform, enabling scientists to engage in debate with the various 'stakeholders' interested in the beneficial application and dissemination of the new knowledge. The conference 'Genetics and the Future of Europe' is the first initiative in this context.

## ...and its Members

Supported by a secretariat in the Research Directorate-General, the Life Sciences Group numbers 11 members, chosen for their eminence in the life sciences and related applications, their public standing and credibility, and their ability to share their knowledge with non-experts. Here is a brief presentation of the LSHLG members.

**Professor Axel Kahn**
President of the LSHLG

Professor Kahn (MD, PhD) works at Institut Cochin (Paris, France) where he is Head of the Research Unit of genetic and molecular physiology and pathology. His research focuses on genetics, gene therapy, cancer, development and physiology. He has written four books on modern biology, genes, and ethics, and counts some 400 publications in international journals. For nine years he presided over the Biomolecular Engineering Committee of the French Ministry of Agriculture. He is currently a Member of the French National Consultative Ethics Committee. He has received several honorary distinctions and has contributed enormously to discussions in the media on the ethical, social, and economic aspects of genetics, biomedicine, and the biotechnologies.



**Professor Victor de Lorenzo**
Vice-President

Professor de Lorenzo works at the National Centre of Biotechnology in Madrid. His research focuses on the molecular biology and genetic engineering of microorganisms for environmental bioremediation. He belongs to the Editorial Boards of five international scientific Journals of Microbiology and Microbial Ecology. He is a member of the European Molecular Biology Organisation and of the European Environmental Research Organisation. He has served in the OECD ad hoc Committee of Governmental Experts in Biotechnology for a Clean Environment and as a National Delegate and core group member of the Standing Committee for Life and Environmental Sciences of the European Science Foundation.

# genetics and the future of Europe

## Sir Tom Blundell

Sir Tom Blundell currently works at the University of Cambridge (UK), where he is the *Sir William Dunn* Professor and Head of the Department of Biochemistry. His research focuses on structural and molecular biology in relation to medicine, agriculture, and modern biotechnology. His work has brought him several awards and prizes and has led to rational approaches to drug design and protein engineering. He is a member of EMBO and Academia Europaea and a Fellow of the Royal Society. He has conducted studies in agriculture and the environment in China, India and Africa. As local councillor and Chairman of the Planning Committee of Oxford in the early seventies, he was involved in improving the urban environment. He has also played an active role in Europe, notably as a member of the European Science and Technology Assembly.

## Professor Derek Burke

Professor Burke is currently a member of the Governing Body of the Institute for Food Research in Norwich (UK) and of the Science, Medical and Technology Committee of the Church of England's Board for Social Responsibility. Since 1995, he has been specialist adviser to the House of Commons Select Committee on Science and Technology. During a research career devoted to the study of influenza virus and interferon, he notably led the group that cloned the human interferon genes and made the first monoclonal antibody against human interferon. As Vice-President and Scientific Director, he also helped to start Allelix, Canada's biggest biotechnology company. He has been active on various boards and committees focusing on science, engineering, and technology, and he contributed to a recent report on "Genetically Modified Crops: the Ethical and Social Issues".

## Professor Patrick Cunningham

Professor Cunningham is currently Professor of Animal Genetics at Trinity College Dublin (Ireland) and Chairman of the Irish biotechnologycompany IdentiGEN Ltd. He was written two books and counts over 200 scientific papers. His research has focused on quantitative genetic theory, the efficiency of livestock improvement programmes, the genetics of cattle, horses and salmon, and on the use of molecular methods in studies on domestic animal evolution and diversity. Professor Cunningham has been Director of the Animal Production and Health Division of FAO, visiting professor at the Economic Development Institute, of the World Bank and President of the European and World-Associations of Animal Production.

**Professor Anne McLaren**

Professor McLaren is currently Principal Research Associate in the Wellcome/CRC Institute (Cambridge, UK) and Professoral Fellow at the Department of Zoology at the University of Melbourne (Australia). Her research focuses on the reproductive biology, developmental biology, and genetics of mammals: physiology and immunology of reproduction, sex determination and the development of primordial germ cells, gene expression during development, and maternal effects. A winner of several awards, she has published two scientific reference books and some 300 publications in scientific journals. She is active in national and international committees, among which the UK Government's Panel on Sustainable Development, the Human Fertilisation and Embryology Authority (a statutory licensing authority), and the European Commission's Group of Advisers on the Ethics of Biotechnology.

**Professor Leonardo Santi**

Professor Santi works at the Centre of Advanced Biotechnology (Genoa, Italy), where he is Head of the Department of Oncology, Biology, and Genetics, of the Postgraduate School of Oncology, and of the University School for Technicians in Biotechnology. He has written over 250 scientific publications in experimental oncology and oncological pathology, with emphasis on lung cancers, occupational tumours, and biological response modifiers. Among other responsibilities at national level, he is Chairman of the Italian National Committee for Biosafety and Biotechnology and Coordinator of the Ministry of Health National Cancer Committee. He is a member of a variety of national and international scientific organisations and is on the editorial board of many international scientific journals.

**Professor Marc Van Montagu**

Professor Van Montagu was formerly Full Professor and Head of the Laboratory of Genetics at the University of Gent (Belgium) and part-time professor at the Free University of Brussels (VUB). His main fields of research are cell biology, chemistry, virology, biotechnology, engineering, and microbiology. He is well known (with J. Schell) as the inventor of *Agrobacterium tumefaciens* transformation technology, now used worldwide to produce genetically engineered plants. Having contributed to founding the Belgian biotech company Plant Genetics Systems, he was its Scientific Director for four years and a Member of its Board of Directors. He has won numerous prizes, is a member of many scientific societies, and is on the Editorial Board of more than ten scientific journals. He has produced over 750 publications.

**Professor Hans Wigzell**

Professor Wigzell is currently Director-General of the Swedish Institute for Infectious Diseases and President of the Karolinska Institutet (Stockholm, Sweden), where he is a professor in the Department of Immunology. His main fields of research are medicine, pathology, and immunology, with emphasis on topics such as the regulation of antibody synthesis and of transplantation immunity, describing and analysing components of the immune system, immunity in the maternal-foetal context, immunity in relation to HIV and other infections, DNA as a tool in diagnosis and gene analysis. Professor Wigzell is an Honorary Life Member of the American Society for Immunology and an elected Member of the Danish Academy of Sciences and Letters. He has published over 560 papers in international journals.

**Professor Ernst-Ludwig Winnacker**

Professor Winnacker works at the University of Munich (Germany) where he is Full Professor of Biochemistry and Chairman of the Laboratory of Molecular Biology. His main fields of research are the molecular biology of DNA replication and recombination and, more recently, prion diseases. Professor Winnacker is President of the German Research Association and has served on several advisory committees. He is notably a corresponding member of a committee established by the German Bundestag to assess the opportunities and risks of recombinant DNA technology. He has published his work in over 100 scientific papers and is the author of several books.

**Professor Rolf Zinkernagel**

Professor Zinkernagel received the Nobel Prize for Physiology or Medicine in 1996, for discovering how the immune system recognises virus-infected cells. His background includes medicine, microbiology, physiology, pathology, and immunopathology. He is currently Head of the Institute of Experimental Immunology at the University of Zurich (Switzerland). He belongs to some 30 honorary or professional organisations and has been on the editorial board of 34 scientific journals. Over the past few years he has been actively promoting public understanding of gene technology, animal experiments, and science in general.

For further information visit
The Genetics and the Future of Europe website on the Europa server:

http://europa.eu.int/comm/research/quality-of-life/genetics.html

The Genetics and the Future of Europe discussion platform was the starting point for a dialogue in which anyone concerned by the importance of the changes being brought about by progress in the life sciences is welcome to take part. Ideas, proposals for action and other initiatives should be sent to:

quality-of-life@cec.eu.int