Preliminary Agenda

Thursday 28 January 2010

Session I: Genetic testing and brain diseases 9.00-13.00
Chair: Borut Peterlin; University Medical Centre Ljubljana, Slovenia

Title TBC

Paolo Gasparini; IRCCS-Burlo/University of Trieste

Genetic testing in Alzheimer’s disease
Raquel Sanchez Valle; Hospital Clinic Barcelona, Spain

Genetic testing in Parkinson’s disease
Nicholas Wood; University College London, UK

The predictive test for Huntington’s disease: a paradigm
Marina Frontali; National Research Council, Italy

Massively parallel sequencing of autosomal recessive ataxia genes
Hans Scheffer; Radboud University Medical Centre Nijmegen, The Netherlands

Session II: Social and ethical challenges 14.30-18.00
Chair: Holger Breithaupt; EMBO reports, Germany

Title TBC

Margit Sutrop; University of Tartu, Estonia

Destiny Lost - Ethical and Legal Implications of Genetic Testing for Neurodegenerative Diseases
Judith Sandor; Central European University, Hungary

Evaluating the added value of genetic tests: a health economist’s perspective
Katherine Payne; University of Manchester, UK

“Send your saliva sample and know your fate” – Direct to Consumer Genetic Testing via the Internet
Leonhard Hennen; Institute for Technology Assessment and Systems Analysis, Germany

Predictivity and protection of human rights
Laurence Lwoff; Council of Europe
**Session III:** Public opinions and personal perspectives  9.00-12.30

Chair: István Palugyi; Népszabadság, Hungary

Title TBC

Agnes Allansdottir; University of Siena, Italy

Alzheimer Europe and its position on genetic testing

Dianne Gove; Alzheimer Europe

Genetic counselling in neurodegenerative disorders

Helena Kääriäinen; National Institute for Health and Welfare, Finland

Parkinson sneaked into our family

Verena Schmocker; Luzern, Switzerland

Neurogenomics, identity and self-management

Hub Zwart; Centre for Society & Genomics, The Netherlands

**Round table and final discussion**  14.00

Chair: Gianna Milano; Milan, Italy

**Public event in town – Title TBC**  17.30
Abstracts and biographies

Session I: Genetic testing and brain diseases

Raquel Sanchez-Valle; Hospital Clinic, Barcelona, Spain

Genetic testing in Alzheimer’s disease
Less than 1% of cases of Alzheimer’s disease (AD) are caused by a specific genetic defect. Causal mutations have been found in three genes: amyloid precursor protein and presenilin 1 (PSEN1) and 2. Mutations in PSEN1 are the most frequent and 177 missense mutations have been described. As each gene should be analyzed in small pieces, the sum of studies needed to investigate if a patient suffers from genetic AD make genetic studies too time consuming and expensive to be performed routinely. Genetic testing is then restricted to those cases with an autosomal dominant pattern of inheritance and early-onset. Most AD cases are, however, not caused by a point mutation. Even though, heritability, that is how much the genetic background explains a disease, is about 70% in AD. Up-to-date, only the presence of the allele ε4 of APOE has been unequivocally established as a genetic risk factor for AD. However, new technologies, with studies of thousands of subjects, will probably identify new risk factors. Epidemiological studies of genetic risk factors provide valuable information about the molecular basis of disease. Nevertheless, the management of information about genetic risk factors at the individual level is controversial from technical and ethical points of view.

Background reading:
- Alzheimer Research Forum;
- The Alzheimer Disease & Frontotemporal Dementia Mutation Database;

Biography
Raquel Sanchez-Valle received her MD degree in 1995 from the University of Santiago de Compostela and her PhD degree in 2003 from the University of Barcelona. She completed her neurology residency at the Hospital Clinic (Barcelona) in 2000 and a fellowship on behavioural neurology at the Alzheimer’s Disease and Other Cognitive Disorders unit (ADOCDU) of Hospital Clinic, including a short-term fellowship at the UCSF Memory and Aging centre, in 2006. Since 2006 she is an attendant neurologist at the ADOCDU. She is actually in charge of the “Genetic counselling program for familial dementia (PICOGEN)”.

Nicholas Wood; University College London, UK

Genetic testing in Parkinson’s disease
There has been a revolution in our molecular genetic understanding of Parkinson's disease. Twenty years ago Parkinson's disease perhaps was considered the archetype of the non-genetic disease. It is now clear that a growing list of genes is primarily responsible for Mendelian forms of Parkinson's disease. It is also clear from recent studies that, due to reduced penetrance, some of these ‘Mendelian genes’ play a role in so-called sporadic disease. This clearly has impact in counselling of patients,
brains in dialogue on genetic testing, Trieste, Italy

guiding the families and developing systematic genetic testing paradigms. The current state of the art will be discussed.

Background reading:

Biography
Nicholas Wood is Galton Professor of Genetics at UCL and also head of Department of Molecular Neuroscience at UCL Institute of Neurology. He qualified in medicine from the University of Birmingham, undertook Neurology and Neuroscience training at the University of Cambridge where he obtained his PhD and for the last fifteen years has worked at the National Hospital for Neurology and Neurosurgery and the UCL Institute of Neurology. He has been head of the Molecular Genetics DNA diagnostic laboratory at the National Hospital for Neurology and Neurosurgery since 1995. He has led his own research group since this time and was made Head of Department of Molecular Neuroscience in 2001. His research interests focus on genetic approaches to Parkinson's disease and the translation of these discoveries into clinical practice.

Marina Frontali, Institute of Neurobiology and Molecular Medicine, CNR, Rome, Italy

The predictive test for Huntington's disease: a paradigm.
Huntington's disease (HD) is a genetic adult-onset neurodegenerative disorder leading to progressive motor, mental and psychiatric disabilities for which there is no cure or prevention. There is a 50% risk of inheriting the disease from an affected parent. HD is caused by a mutation which can be easily detected through a genetic test. Since the first steps towards the availability of the test it was immediately clear that its result could have far reaching consequences on the psychological, social and ethical ground, particularly for healthy at risk persons undergoing a predictive test, in a situation in which no medical benefit could ensue. This led to publish in 1994 the first guidelines for a predictive genetic test based on the principle of autonomy of decision of persons at risk and confidentiality about the result. The management of these tests became, since then, a complex procedure aimed at assisting at risk people in their decision about the test through an extended communication process with a team of professionals, who should abandon any directive attitude, and help, instead, the counselees to gain control over their lives by analyzing pros and cons of having the test done, not in abstract but in their specific psychological, social and ethical situation. The different attitudes, responses, expectations, needs and problems of persons at risk when confronted with the decision about the test and the different ways in which a test result can impact on their lives emerged very clearly with this counselling procedure, so diametrically divergent from the paternalistic directive attitude of medical professionals. What will happen, however, of all this in the future? For the plethora of private labs offering the test online just, the guidelines for the predictive test are certainly not coherent with their profit. But also the advancement of scientific knowledge could make obsolete the actual counselling procedure. What would happen if a drug will become available to delay or prevent the disease onset? Even if in the future the management of predictive test will be completely changed and a more directive attitude will re-emerge, some lessons from the experience...
collected so far should be learned such as the need to leave more space to the feelings and the subjectivity of the persons at risk.

**Background reading:**
- European Huntington Disease Network (EHDN).

**Biography**
Marina Frontali is associate director of research at the Institute of Neurobiology and Molecular Medicine of CNR, Professor of Clinical Genetics at the School of Specialization in Medical Genetics at Tor Vergata University of Rome, member and subcontractor of the European Huntington’s Disease Network (EHDN), co-leader of the EHDN Working Group on Genetic Testing and Counselling, Genetic Counsellor at Policlinico Tor Vergata and Ospedale S. Andrea, Rome. Her research has contributed to several aspects of Huntington’s Disease, from epidemiology to mutation characterization, from age at onset variability and its modifier genes to ethical and psychosocial aspects of predictive testing and finally to the beneficial effects of rehabilitation therapy.

**Hans Scheffer:** Department of Human Genetics, Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands

**Massively parallel sequencing of autosomal recessive ataxia genes**
Massively parallel sequencing has tremendous diagnostic potential for the simultaneous analysis of many disease genes in genetically highly heterogeneous disorders, e.g. Parkinson’s disease or autosomal recessive ataxia. At present, clinically meaningful genetic tests are predominantly available for monogenic disorders (one gene – one phenotype). However, the majority of genetic diseases are molecularly and clinically highly heterogeneous, and until recently the available techniques lacked the required capacity to analyze several genes in parallel. The recently introduced next generation sequencing technology now offers the unique opportunity to develop tailor-made approaches for molecular genetic research and diagnosis of heterogeneous disorders. We will present the validation of an array-based sequence capture method for medical resequencing approaches in autosomal recessive ataxia. Eight subjects with 10 known pathogenic mutations were studied. Genomic sequences of seven well described disease genes were targeted on a single oligonucleotide array. After enrichment each of the patients’ DNA samples was analyzed by Roche GS FLX Titanium sequencing. This approach enabled detection of known deletions and hetero- and homozygous point mutations in all 10 mutant alleles, as well as more than 99% accuracy for known SNP variants. We conclude that massively parallel sequencing of enriched samples enables tailor-made genetic diagnosis of heterogeneous genetic disorders.
Background reading:
- TECHGENE, European project focused on the use of massively parallel sequencing techniques for the development, optimisation and implementation of diagnostic tools for genetic disorders;

Biography
Hans Scheffer is head of the Division DNA Diagnostics within the Department of Human Genetics, Radboud University Nijmegen Medical Centre (RUNMC). His main activities are genetic research and clinical molecular genetic diagnostics, with a focus on neurogenetic disorders. He is coordinator of the FP7 TECHGENE project. Within TECHGENE, entirely new next generation sequencing techniques including automated data analysis/interpretation in molecular research and DNA diagnostics will be developed, validated and implemented, in particular for genetically heterogeneous disorders. He is involved in several research projects in neurodegenerative disorders, e.g. in autosomal recessively inherited ataxias, and in Parkinson’s disease.

Session II: Social and ethical challenges

Chair: Holger Breithaupt, EMBO reports, Science & Society, Heidelberg, Germany.

Biography
Holger Breithaupt has been the editor for the Science & Society section of EMBO reports since the journal’s launch in 2000. He studied biology and computer science at the University in Cologne, Germany and holds a PhD from the University of Dusseldorf in Germany. He graduated from the Science and Environmental Reporting Program at New York University and worked as a freelance science journalist before he joined EMBO reports.

Judit Sándor; Centre for Ethics and Law in Biomedicine, Central European University, Budapest, Hungary

Destiny Lost - Ethical and Legal Implications of Genetic Testing for Neurodegenerative Diseases
Disease is a complex socio-pathological condition that casts patients into the realm of the unexpected and unwanted. It is an unbidden condition to be cured or at least its symptoms mitigated by some form of medical treatment. At least this is the way we thought about diseases before the emergence of predictive and asymptomatic genetic testing.
Diseases have various cultural, psychological, social, ethical and personal meanings. The stigmatization of hereditary diseases in society may lead to ethical and legal consequences that are difficult to grasp. The stigma associated with neurodegenerative diseases would be even harder to bear if the disease is proven to be hereditary by some form of genetic testing. And even if genetic information is strictly

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sealed with the legal guarantees of privacy, knowing something that is someone’s future destiny may provoke the individual to reconsider his or her ambitions and abilities, future career and family planning. Moreover, if the seal of privacy is broken, knowing the conclusions of a genetic diagnosis may yield to potential harm in various forms of discrimination, such as different attitudes by health care workers, insurance companies, employers, or family members. At present it is difficult to make an assessment on the overall effects, especially because genetic tests are so far available for only a tiny fragment of the diseases. Those who have already been tested, and as a result they know their biological destiny, this knowledge places them in a special minority group within society.

According to widely respected European norms “when a genetic test is envisaged, the person concerned shall be provided with prior appropriate information in particular on the purpose and the nature of the test, as well as the implications of its results.” This seems to be a general statement in need of further elaboration. The presentation will make an attempt to explore the complex ethical and legal dilemmas that should be assessed before working on the adequate protocol of informed consent and genetic consultation on these specific conditions.

**Background reading:**


**Biography**

Judit Sándor is Professor at the Central European University (CEU), Budapest. In 1996 she received Ph.D. in law and political science. She was one of the founders of the first Patients' Right Organization (‘Szószóló’) in Hungary; she is a member of the Hungarian Science and Research Ethics Council, and works also at the Hungarian Human Reproduction Commission. In 2003 she was appointed as an expert for the Prime Minister’s Advisory Committee on Human Genetics. In 2004-2005 she worked as the Chief of the Bioethics Section at the UNESCO. She published six books in the field of human rights and biomedical law. Her works appeared in different languages including Hungarian, English, French and Portuguese. Since September 2005 she is director of the Centre for Ethics and Law in Biomedicine (CELAB) at the Central European University.

**Katherine Payne**, Health Methodology Research Group, School of Community Based Medicine, The University of Manchester, UK

**Evaluating the added value of genetic tests: a health economist’s perspective**

Genetic tests compete with other healthcare services for scarce resources but can facilitate more rapid and accurate diagnoses of genetic conditions and predict outcomes for individual patients and potentially prevent disease, prolong life and promote health. Genetic testing is likely to have an insidious effect on future healthcare resources in part due to the lack of a regulatory framework supporting the development of a robust evidence base. This presentation will give an overview of the current funding and regulatory climate for genetic tests, including a brief description of the role of decision-making bodies, such as the National Institute for Health and Clinical Excellence and the UK Genetic Testing Network. I will introduce how to apply the concept of opportunity cost to genetic tests, which drives health policymakers to consider the benefits forgone if one healthcare intervention is chosen over
the other available options. The presentation will conclude with my view of a research and policy agenda to promote the use of genetic tests in a way to achieve maximum benefit for patients.

**Background reading:**
- The National Institute for Health and Clinical Excellence (NICE);

**Biography**
Katherine Payne has over 15 years experience as an academic health economist and an international reputation for the economics of genetic technologies and services. Katherine is a senior research fellow in health economics based in the Health Methodology Research Group, The University of Manchester. She has an honorary position with Nowgen – A Centre for Genetics in Healthcare. In October 2003, Katherine became a member of an NICE Appraisal Committee. She currently holds a RCUK Academic Fellowship to develop methods and evaluate genetics technologies and services.

**Leonard Hennen:** Institute for Technology Assessment and Systems Analysis, Bonn, Germany

“**Send your saliva sample and know your fate**” – Direct to Consumer Genetic Testing via the Internet.
At the end of the 1990s, genetic testing offered directly to consumers came onto the market as a new “business model”. Up until then, genetic testing had been carried out by specialised institutes in the medical sector upon referral by a medical doctor. In recent years, new companies offering direct-to-consumer genetic testing (DCGT) via the internet alone are emerging constantly. This method of “bypassing” the medical sector with its established ethical and quality standards has given rise to concerns regarding an uncontrolled growth of the market for genetic testing. Tests are offered whose clinical validity and utility is doubtful and thus could do harm to consumers who might be misled and insufficiently informed by the DCGT companies’ advertisements.

The presentation will summarize the findings of a project carried out on behalf of the European parliament on DCGT that provided an overview of the current discussion on DCGT among experts and public authorities and on the current status of DCGT offers on the internet. Guided by an analysis of the market development and the pros and cons of DCGT, the project explored possible options and needs for political intervention.

**Background reading:**
- Report for the European Parliament on Direct to Consumer Genetic Testing;
- A Common Framework of Principles for direct-to-consumer genetic testing services by the UK Human Genetics Commission;
- Examples of leading companies for DCGT: 23andMe and deCODEme.
Biography
Leonard Hennen studied sociology and political sciences (M.A.) and obtained a doctorate in sociology from Technical University Aachen, Germany. After five years as a social researcher at the department of Technology and Society at the National Research Centre Jülich, Germany (projects on "technology and everyday life", "risk-communication"), he was from 1991 to 2005 project manager at the Office of Technology Assessment at the German Parliament, which is run by the Institute of Technology Assessment, Research Centre Karlsruhe. He has been responsible for Technology Assessment (TA) projects on Genetic Testing, Pre-implantation Diagnostics, and Brain Sciences as well as for projects on public acceptance of technologies and technology controversies, Sustainable Development, Research Policy and others. He participated in several European projects on concepts and methods of TA. Since 2006 he has been coordinator of the European Technology Assessment Group (ETAG) carrying out TA studies on behalf of the European Parliament. His research interests include Sociology of Technology, Technology Policy, Concepts and Methods of Technology Assessment, TA in the field of Biomedicine.

Session III: Public opinions and personal perspectives

Chair: Istvan Palugyai, Népszabadság, Hungary

Biography
Istvan Palugyai is a journalist, senior science editor of Népszabadság (the biggest and most influential serious daily paper in Hungary) where he is responsible for the weekly science, medicine, environment, technology and the IT columns since 1991. After studying biology and behavioural genetics, he worked as TV moderator, editor and producer of popular science programs, science reporter of other Hungarian daily (Magyar Hírlap, 1979-1991). He is President of the Club of Hungarian Science Journalists (CHSJ), Leader of the only existing science and environmental journalism training course in Hungary organized by the CHSJ, President of the European Union of Science Journalist’s Associations, (EUSJA), Vice President World Federation of Science Journalists (WFSJ) and was the Chief Organizer of the Second World Conference of Science Journalists, 1999, Budapest.

Agnes Allansdottir; University of Siena, Italy

Background reading:
- Eurobarometer Survey Europeans and Biotechnology in 2005: Patterns and Trends (report and executive summary);
- Eurobarometer Survey Social Values, Science and Technology (report);
- Eurobarometer Survey Europeans, Science and Technology (report).

Biography
Agnes Allansdottir is a social psychologist at the University of Siena. She studied in her native Iceland, France and the UK where she participated in the early empirical efforts on Public Understanding of Science. She has lead research groups in international collaborative work on science and society from the mid nineties, with a particular attention towards European opinion and communication processes relating to genomics and society. She is a


**Dianne Gove**; Alzheimer Europe, Luxembourg

**Alzheimer Europe and its position on genetic testing**

This presentation will provide background on Alzheimer Europe which is an umbrella organisation of national Alzheimer Associations for carers and people with dementia. It will be briefly explained how it is organised, its objectives, some of the work it has carried out and its current work.

Alzheimer Europe’s position on genetic testing will then be presented covering arguments for and against genetic testing linked to the limitations of tests, the importance of counselling, possible negative implications such as stigma and discrimination, the use of tests for research purposes, data protection and the use of genetic testing by insurance companies.

**Background reading:**

- Alzheimer Europe’s position paper on genetic testing.

**Biography**

Dianne Gove has been working at Alzheimer Europe since 1996 and has been in charge of a number of projects such as the writing of care manuals, drafting legal recommendations on the rights and protection of people with dementia and carrying out a survey of social support available in Europe. Her current projects include updating national legal reports, setting up a dementia research observatory and exploring the ethical issues related to assistive technology. She has an honours degree in psychology, MAs in education and psychoanalytic studies and is currently carrying out research into dementia-related stigma.

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**Helena Kääriäinen,** National Institute for Health and Welfare, Helsinki, Finland

**Genetic counselling in neurodegenerative disorders**

Parallel with the development of genetic knowledge, patients and relatives are increasingly interested to learn more about their rare hereditary diseases and risks to get them. In genetic counselling a specialist in genetics (medical geneticist, genetic counsellor or genetic nurse) communicates with the clients medical facts of the disorder including its heredity and the risk of recurrence, helps them to understand the options for dealing with the risk of recurrence and helps them to use this genetic information in a way that promotes health, minimizes psychological distress and increases personal control. In this way they are believed to make the best possible adjustment to the disorder in their family.

Neurodegenerative diseases are a special challenge for genetic counselling. There are ways, including genetic testing, to predict future severe illness but very limited means to prevent or postpone the disease. In spite of that, many families want to know the exact etiologic diagnosis, their risk estimation and, in many cases, also the exact risk based on presymptomatic genetic testing. All this creates severe questions concerning their personal well being but also societal aspects like questions related to occupation and insurance.
Background reading:


**Biography**

Helena Kääriäinen is a specialist in medical genetics. Since 2007 she has been a Research Professor at National Institute for Health and Welfare in Helsinki, Finland. She has been board member and president of the Finnish Society of Medical Genetics, and a member of several national committees, including National Advisory Board of Health Care Ethics. She has had an active role in genetics in Europe, including Secretary General of ESHG since 2003 and member of committees of CoE concerning genetic testing. She has organized several international workshops and written and edited books for medical doctors and lay people. In EuroGentest project her task has been to create guidelines and tools for improving the quality of genetic counselling. Her research interests are rare diseases, genetic testing and counselling.

***Verena Schmocker;*** Luzern, Switzerland.

**Parkinson sneaked into our family**

For many years I have known that Parkinson Disease is in our family. When my mother was diagnosed with PD, since our grandmother had it as well, we realised that it runs in our family and that only females get it. My sister and I started to worry that we will be the next ones to get it. But we never thought about taking a test. Does it change anything? Is it easier to live when you know you are going to get it?

Then 5 years ago I got to know I had PD. It changed my life. How do I handle it with own children? After a consultation with a Professor of genetics I decided not to take a test. He advised me to go on with my life as usual because hopefully medical science could find a medicament to heal PD. My own life experience taught me to go this way. I always think or even try to think positive. To be always afraid about it, is a negative way and gives the PD nutrition. I tell that to my daughters and I show them that you can still live a good life even with PD.

**Background reading**

- [Understanding Parkinson's](https://www.parkinson.org) by the Parkinson’s Disease Foundation;
- [Understanding Parkinson's Disease](https://www.webmd.com) by WebMD;
- [Rewrite Tomorrow](https://www.epda.org) by the European Parkinson’s Disease Association;
- [EuroGenGuide](https://www.europarkinson.org), European project providing information about genetic testing, counselling and research across Europe.

**Biography**

Verena Schmocker is a chemist and worked in different pharmacies until she got married in 1984, when her “family time” started. For many years she knew they have Parkinson Disease in their family (grandmother/mother). Five years ago she got to know she had PD too. Verena founded together with the Parkinson Association Switzerland a self-help group for young patients; right now she has 20 people with their partners. She is also in contact with the European Parkinson Association (EPDA). Verena does presentations and training programmes in Hospitals, Nursing Homes, Nurse Education and television in Switzerland, to educate and help understand people with PD.
Hub Zwart; Centre for Society & Genomics and Radboud University Nijmegen, Nijmegen, The Netherlands

**Neurogenomics, identity and self-management**

Genomics and brain research are revolutionary fields drawing considerable attention from science and media, not only because of spectacular breakthroughs (genome sequencing, brain imaging), but also because of possible implications for health and for how we see ourselves. Both fields now “merge” into neurogenomics. What are the implications for human identity, for agency and self-reflection? How will bioinformation provided by genetic tests affect the way we live our life, pervading everyday existence, life-style, career choice and the like? Will it lead to empowerment, improving prospects for self-management? Neurogenomics entails the promise that individuals become the managers of their own health, actively postponing degradation later in life through diet and life-style when still healthy. Neurogenomics may invoke individuals to take an entrepreneurial stance, as entrepreneurs of their own life history, managing their genetic “capital”, calculating, seizing and preventing opportunities and risks. Neurogenomics may add to this image, this use of personalized bioinformation by individuals, but also open up opportunities for enhancement, counteracting weaknesses and risks in an anticipatory manner, combining neurogenomics with psycho-pharmaceutics or bioimplants. The agenda of neurogenomics results from a dialogue between research and debates and uses of new forms of bioinformation by society.

**Background reading:**

- **From genetic risk to post-genomic uncertainties: the birth of the “genetic entrepreneur”**, Harvey A. New Genetics and Society 2009; 28 (2) 119 – 137;

**Biography**

Hub Zwart if full Professor of Philosophy, Faculty of Science, Radboud University Nijmegen, chair of the department of Philosophy & Science Studies, director of the Institute for Science, Innovation & Society and scientific director of the Centre for Society & Genomics. He studied philosophy (cum laude) and psychology (cum laude) in Nijmegen, worked as research associate at the Centre for Bioethics (Maastricht) and defended his thesis in 1993 (cum laude). He was research director of the Centre for Ethics (Nijmegen) and in 2000 became full Professor of philosophy at the Faculty of Science. He was European lead of the EU Canada exchange program Coastal Values. In 2004 he became director of the Centre for Society & Genomics. The focus of his research is on philosophical and ethical issues in the life sciences (biomedicine, animal research, environmental research, (post)genomics).
**Round table and final discussion**

**Chair:** Gianna Milano; Milan, Italy

**Biography**
Gianna Milano graduated at Bocconi University, Milan. She specialized in scientific journalism at New York University in 1984. In 1992/1993 she was granted a Knight Science Journalism Fellowship to further her studies at the Massachusetts Institute of Technology. She was chief editor for science and medicine at the weekly magazine *Panorama* for twenty years and now she works as freelance journalist. After creating “OpenLab”, a course for science journalists at the University of Pavia, her dedication to improve the quality of scientific information and the relationship between media, science and society grew even more intense. Since 2003 she teaches scientific journalism at SISSA, Trieste. She is the author of several books in Italian such as: *Blood and HIV, The story of an Italian scandal*, Il Pensiero Scientifico Editore, 1995; *Bioethics, from A to Z*, Feltrinelli 1997; *When a child does not know how to read*, Rizzoli 2000; *The revolution of stem cells* (with C. Palmerini) Feltrinelli, 2005; *Diary of a timely death* (with M. Riccio) Sironi, 2008.