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Conclusion

A Short History of This Anthology

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The journey to this book¹

This book began during a marathon, and so far, it ends with the Declaration on Freedom of Scientific Research, found in Appendix A. Let us begin with the end. The Declaration is the document signed by the participants to the World Congress on Freedom of Scientific Research. It is of course a succinct expression of a variety of values and beliefs, connected by the common denominator of faith in scientific progress. Although the Declaration perhaps is only a summary of much more elaborate arguments proposed in contributions such as those in this volume, we decided to add it here for two reasons. One is that it is an important symbol of the common effort of people coming from different states, religions, backgrounds and cultural context, to defend the progress of science. The other reason is that this Declaration highlights the importance of ethical and philosophical reasoning to political action. Politics provides the hinge joint that links theoretical debates to civil society. In the case of science, politics aims at ensuring that the potential beneficiaries of scientific development do actually obtain the advantages that science may promise, while also attempting, through regulation, to secure ethical practice in science.

It all began, we mentioned, while running a marathon, and not metaphorically. This is how we, as an Association, were born, and how this book was first thought of. Luca Coscioni (who funded the Association that took his name) was a university Professor of Economics as well as a marathon runner, involved in local politics in his native Viterbo as a member of the city council. In 1996, while training for the New York Marathon, he was diagnosed with amyotrophic

lateral sclerosis (ALS). In five years, he was confined to a wheelchair. In 2000, Luca decided to bring his health situation to the general public as a political case, denouncing the lack of appropriate regulation and public funding for scientific research, in particular that on embryonic stem cells, in Italy. The same year, he was elected member of the General Council of a political organisation affiliated with Italy's Nonviolent Radical Party Transnational and Transparty (NRP). At the 2001 Italian parliamentary elections, Luca ran for the Chamber of Deputies in the same list as former European Commissioner Emma Bonino, who is also a contributor to this anthology. Although Luca was not elected to Parliament, he received the support of hundreds of scientists, physicians, patients as well as politicians and intellectuals, and fifty Nobel laureates. On that occasion the Nobel Laureate for Literature Josè Saramago wrote a message of support for Luca:

Perhaps the support of a mere writer like me will seem a little or a lot out of place in a list of scientific leaders who, with their names and their prestige, seal the words spoken by Luca Coscioni. In any case, my name is at your disposal, so that the light of reason and human respect can illuminate the gloomy spirits of those who believe themselves to be, still and always, the masters of their destinies. For a long time we waited for the day to break, we were exhausted by the waiting, until all of a sudden the courage of a man, rendered silent by a terrible disease, gave us renewed strength.

In 2002, together with Emma Bonino and Marco Pannella, Luca founded the Luca Coscioni Association, with the aim of promoting freedom of scientific research not only in Italy, but internationally, with particular attention on research on embryonic stem cells, a technique that risked being severely hindered by a draft bill before the Italian Senate, and which has been widely debated and prohibited in many other countries.

In 2004 the Associazione Luca Coscioni and the NRP founded the World Congress for Freedom of Scientific Research as a permanent forum of activities to promote freedom of scientific research worldwide. The First World Congress was held in Rome in 2006. This is where this anthology began to be conceived.

At that time, Luca was President of the Association, and in spite of the severe degenerative illness that rendered him immobile, on the first day of the Congress, just days before his death, he eloquently expressed his appeal. This not only touched everyone present, but also reminded us all that when we talk about scientific research, we talk about real people, who have real lives, suffer real illnesses, and who are destined to die prematurely and in agony unless treatment is found – and hope for treatment for many degenerative diseases bears upon stem cell research. Luca made his appeal with these words:

The first meeting of the World Congress for Freedom of Scientific Research comes at a particularly difficult time in my life... Amyotrophic lateral sclerosis does not limit intellectual skills, it makes you fully aware of feelings of despair and fear

of lifetime. A time which is violently becoming narrower and which forces me to address the urgency of the price that millions of people around the world are paying and will have to pay to a culture of power, a culture of class...imbued with anti-scientific dogmas and prejudices, which exclude scientific knowledge and which exclude individual freedom to benefit from knowledge. Stakes are too high to let time pass, more time pass... To the violence of this cynical prohibition on scientific research and on the fundamental rights of citizens, I have responded with my body, which maybe many would have liked to see just as a hopeless prison, and today I respond with my thirst for air – because I am truly breathless – which is my thirst for truth, my thirst for freedom.

A unique feature of the First World Congress for Freedom of Scientific Research was that it represented a unanimous appeal coming from the Campidoglio, in Rome, in the very centre of the ‘Eternal City’. The geographic location not only had symbolic but also political significance. The historical importance of the place is exemplified, for instance, by the choice of Campidoglio as one of the symbols represented on Europe’s coin, the Euro. The Campidoglio was, before Christianity, the place where the pagans devoted their cult to the Goddess Juno, which, due to a peculiar incident, also became called *Moneta*. This is how the story, briefly, is said to have gone.

In the 390s B.C. Rome was besieged by the Gauls. Next to the Temple of the Goddess Juno, sacred geese were bred. One night, as the Gauls unexpectedly arrived, the sacred geese began to squawk so loudly that the Consul woke up and gave the alert. The attack was thus thwarted. It was believed to have been Juno who awoke the geese, and hence she also acquired the name *Moneta*, from the Latin *monere* – to warn, to caution. Over a century later, the mint was edified near to the temple, under the protection of the Goddess Juno, or *Moneta*. From this peculiar fusion, the word *Moneta* started to indicate the currency (hence the word ‘money’).

In addition to being rich in history, the place is of incredible artistic beauty; the main square was designed by Michelangelo Buonarroti and is a place of touristic, artistic and architectonic attraction, as well as of political decisions. However, what is perhaps even more striking is that this place, theatre of lay discussions, is just a few miles away from the Vatican, a small and influential state that has exercised enormous weight on other states’ policies upon freedom of research. As is well known, the pope Giovanni Paolo II and now the pope Benedetto XVI, ex Cardinal Ratzinger, have solemnly condemned embryonic stem cell research, and their potent voice has been welcomed by the governments of several countries, such as Germany, Italy, France, Malta, and Ireland. It is significant that experts from all over the world came to oppose the papal anathema and to explain why freedom of research is so precious to all of us.

A second Congress was organized in Brussels in March 2009, at the European Parliament, and again was a forum of stimulating exchanges between world leading scientists, lay people, European politicians, economists, philosophers and jurists. At that point we decided to make the results of the meetings

available to the international academic community. This volume is perhaps only a small contribution to the international debate on freedom of scientific research, but this, we believe, is not the end. In order to complete a marathon it is imperative to set small goals.

Freedom and science

In the remainder of these conclusions, we would like to offer some reflections on the concept of *freedom* of scientific research, which we also draw from the work of the authors who have contributed to this volume. The expression ‘freedom of scientific research’ usually elicits two opposing types of reservations. The first is that research is free in and of itself, and therefore it does not need anyone to ‘free’ it, rather it needs to be financed. The second is that research cannot be without limits, and needs to be regulated. Both are valid considerations. With regard to the first argument, of course freedom of scientific research includes freedom from financial impediments. However, as arguments in this volume have shown, that scientific research *should be funded* is not always uncontroversial. This issue has been raised, for example, by Piccirillo, in his interesting chapter on astrophysics. Oswald has also made important considerations on this point. Piccirillo in particular not only asked why public money should fund (potentially useless) base research to the detriment of technological applications which could save human lives directly, but even goes as far as suggesting that the choice of funding research may involve the sacrifice of human lives, to the benefit of perhaps greater numbers in perhaps remote future generations. This posits scientific research in the delicate ethical debate about which lives one should save, and poses further issues of whether it may be ethical to surely (or almost surely) lose real lives that could be saved today in order perhaps to improve our capacity to save greater numbers of potential lives in a remote future. We do not want to take a position on this issue: we just want to illustrate that freedom from financial constraints is not everything; of course, in a system of limited resources, financial constraints are inevitable, and the ethical problem arises as to what areas of science should be funded and why. However it can be argued that some financial constraints *should be* in place anyway, that some areas of research *should not be funded* – indeed the ethical suitability of science has to be established before funding is granted.

With regard to the second argument, freedom does not necessarily entail lack of regulation. Baron, Santosuosso and Devaney have made the point well, examining the issue of regulation from a legal perspective. Regulation is needed in every sector of scientific research, from clinical trials to animal testing, from research on nuclear to nanotechnologies, or research with human embryonic stem cells to brain imaging, and so on. The funding system and the technology and scientific knowledge transfer should be regulated, safety

conditions should be checked and accountability to the public ensured, as people may be concerned with risks, be they social, environmental or related to healthcare.

Assessing the ethical suitability of scientific research, and regulating its development through sound and transparent legislation are problems that can be described as both theoretical and pragmatic. One of the authors of this paper, being directly involved with the European Parliament, has witnessed how often the ethical debate does not steer political decisions, but is rather silenced by strong ideological opposition. Political decisions are thus sometimes made without the direction of a serious ethical debate. Ethical analysis should help to evaluate the logical coherence of arguments for and against any given proposed procedure; it should help to evaluate the possible middle and long-term consequences of scientific developments for those involved and for society at large, including future generations and geographically distant populations; it should help to assess the consistency between the various possible options and social policies and laws in place in various countries; and it should help to disentangle which reactions and opinions are based on reasoned judgement, and which are based on superstition, fear or custom. It is the aim of ethical analysis to offer a thorough exploration of the various predicaments over which deliberators are called to make a choice. Politics, in this sense, should be guided by ethical debate, but instead, ethical confrontation is often absent from political debates, and silenced behind the thick wall of ideology. Arguments against (and even sometimes *for*) scientific research often rest on unrefined intuitions, unjustified fears of future catastrophic scenarios, or on declarations of the solemn anthems of Justice, Life, Rights, as resounding as empty, seldom explained or explored in any detail.

Scientific development calls not only for pragmatic action and appropriate regulation, but also reasoned judgement. Human intervention goes now from the initial to the final phases of life, for instance it can split reproduction from sexuality (see Carl Djerassi's contribution to this volume) and can preserve vital functions well beyond what was possible in the past. The possibility to interfere with the human genome means that human evolution is no longer tied to the mechanisms of 'natural' selection – instead it gives the opportunity to act directly and modify the genetic inheritance with no need to undergo the long ages of evolution. These new possibilities raise a set of ethical questions that should be explored rationally as political matters, not only as academic matters, and not be reduced to a confrontation between defendants of 'nature' (as an a-priori good and thus to be protected) and opponents to 'nature' (judged as dangerous and thus to be transcended). A more serious debate, which goes to the heart of the practical issues, and which evaluates the pros and cons of any given procedure for all those involved, is required in order to make sound political judgements. For example, the issues of social justice that can be raised in relation to the possibility of intervening with human genomes should be

considered seriously in both theoretical and political debates. Social justice is (or should be) already at the core of healthcare and welfare policies as far as it concerns the access to traditional medical treatments, and politicians at an international level are acutely aware of issues of social justice, but the problem may become ever more critical when we consider new therapies. In fact since the attempt to ensure that everyone has access to adequate medical assistance is in the general interest, this attempt should be felt as more and more compelling when the issue at stake is not only the opportunity to be treated, but also the possibility to be genetically modified during that treatment.

It is a sadly known fact that the international community is unable to resolve the global imbalances between the vast majority of the human population suffering from treatable diseases and high premature mortality rates, and the small minority of the human population benefiting from the greatest share of healthcare resources. These social disparities may become real anthropological differences, going beyond the single life or generation and being genetically transferred to future generations. Although these issues are serious and should be addressed, they do not grant an absolute reason in favour of refusal of genomic intervention: indeed the ideological barriers sometimes built in front of such innovations prevent us from regulating them through equity and justice. The impoverishment of ethical debate at a political level has hideous consequences on science, and hence on society, because it impinges upon the resolution of the two important issues highlighted above: which areas of science should be given financial priority, and how they should be regulated (Baron and Devaney offer some suggestions in their contributions to this volume).

One final point. As is also pointed out by Corbellini, freedom of science is closely intertwined with the very essence of liberal democracies. This is why, we propose, such freedom does not entail a lack of regulation, but a rethinking of regulation, which makes scientific development ethical and efficient. Proper regulation and public accountability is indispensable to scientists and to citizens. Many in this volume have stressed the importance of a better dialogue between scientists and the general public, and the responsibility of the State, which ought to ensure that proper information about science development be provided to citizens.

The terrain we have covered, since Luca began running back in 2001, is remarkable. Luca himself was able to participate, with the NRP, in a transnational and transparty effort, and called on the European Union to fund research involving embryonic stem cells (Emma Bonino and Simona Giordano write about it in this anthology). Noting that one of the most promising fields in biotechnology is still that of stem cells and that research projects funded by the 7th Framework Program (FP) for Research and Technological Development offer hope and prospects to tens of millions of men and women, the Luca Coscioni Association and the NRP will soon call on the European Parliament, as they did on the adoption of the 7FP, to ensure that the 8th Framework

Program (2014–2020) confirms the funding of research projects on embryonic stem cells, as well as adult stem cells or induced pluripotent stem cells, but that the additional political evaluation – currently realized through a vote by EU national representatives – be abolished. Moreover, the Association and the NRP will urge that eligibility for funding should be extended to research projects based on cell nuclear transfer (often inappropriately called ‘therapeutic cloning’).²

We thus wish to reiterate that scientific research depends on the concerted efforts of many: of the scientists of course, but also of politicians, academics, and lay citizens. With this volume we aimed not only at disseminating the results of our Congress within the academic community, but at promoting a co-operation amongst experts with different backgrounds, one which could be accessible to a non-specialist audience, and that anyone with an interest in science could reach, whether philosopher, economist, jurist or lay person. With this volume, we hope we have stressed the importance of a serious ethical debate within politics, and, more importantly, the importance of sound politics to science and thence to human flourishing.