

Conclusion

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This volume is the result of a long-standing international collaboration which takes the name of the World Congress for Freedom of Scientific Research (www.freedomofresearch.org). After the Third Meeting, held in Rome in April 2014, some of the presenters united in the preparation of this collection. Others interested in science and its regulation joined up along the way. The World Congress has overall brought together hundreds of people, including academics, policymakers, jurists, scientists and disability-right activists from all over Europe, the US, India, Iran and many other countries.

I will keep this conclusion brief, because what the authors have written already provides a great deal of food for thought. But I would like to offer a brief history of the World Congress, and to report some of the achievements obtained through this common international forum. The World Congress for Freedom of Scientific Research is a permanent forum of activities to promote freedom of scientific research worldwide; it was founded in Rome in 2004 by professor of economics Luca Coscioni. Professor Coscioni was diagnosed with amyotrophic lateral sclerosis. Within five years he was confined to a wheelchair, and founded, together with the main leaders of the Radical Party (Emma Bonino and Marco Pannella) a not-for-profit organisation that took his name: the Luca Coscioni Association. The World Congress for Freedom of Scientific Research was created to provide an arena for multidisciplinary and transnational discussion of scientific research, freedom and regulation, not attached to any specific political party. The First World Congress was held in Rome in 2006. At that time, Professor Coscioni was president of the Association, and was already severely ill. Sadly, he in fact died on the last day of the Congress. In a video message to the audience, Professor Coscioni said:

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.

As Marco Cappato and I noted in the conclusion of our first volume on scientific freedom (Giordano et al. 2012), this message reminded us all that when we speak about scientific freedom we are not discussing an abstract idea: we are talking about real people, who have real lives and suffer real vulnerabilities and illnesses. I wish to add now that, as human life has extended so significantly in the last few decades, and as it is even clearer today than it was in 2006 that the process is not going to reverse or stop, it is imperative to remind ourselves that hope for treatment for many degenerative diseases (some of which are likely to come with longevity) bears upon scientific research, including stem cell research. The personal and social implications of scientific freedom and proper regulation is inestimable, as incalculable are the losses resulting from regulation that hinders or prohibits scientific progress unjustly, that bows to a culture not just of obscurantism, but even more worryingly of misinformation and conspiracy.

The first meeting of World Congresses for Freedom of Scientific Research was held in Rome, at the Campidoglio, the second at the European Parliament in Brussels, and the third again at the Campidoglio. The symbolic importance of this particular location needs to be stressed: the Campidoglio is in the very heart of Rome and very close to the Vatican. The square was designed and realised by Michelangelo Buonarroti, and the Campidoglio has been chosen as one of the symbols represented on Europe's coin, the euro. There is an interesting anecdote about this place. Before Christianity, the Campidoglio was the place where the pagans venerated the goddess Juno. Next to the goddess's temple were the 'sacred geese'. Around 390 BC Rome was besieged by the Gauls. It is said that on the night when the Gauls arrived, the sacred geese began to squawk so loudly that the consul woke up and alerted the city. According to the legend, it was Juno who woke up the geese – and after that Juno was also called Moneta, which in Latin means 'to warn, to caution' (*monere*). Incidentally, over one century later the mint was built near the temple, and the goddess Moneta was meant to protect the valuables. From this fusion of mythology and history the word *moneta* began to indicate currency – and hence *money* in English, *monnaie* in French, *moneda* in Spanish, *moeda* in Portuguese, *moneta* in Italian.

Perhaps now more than ever, particularly during the period of the separation of the United Kingdom from the European Union, with all this may imply for science (scientists' mobility, research funding, and so on) it is important to remember the significance of international collaboration – and therefore of forums of these kinds. Science is not just a human activity, but, arguably, a human right. As such science is described and defended in a number of international documents, declarations and covenants. The human right to science is enshrined in Article 27 of the 1948 Universal Declaration of Human Rights;¹ in Article 15 of the 1966 International Covenant on Economic, Social and Cultural Rights;² in Article 13 of the Charter of Fundamental Rights of the European Union;³ in Article XIII of the American Declaration of Human Rights;⁴ in Article 14 of the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, the 'Protocol of San Salvador';⁵ in Article 22 of the Charter of the African Union; in Part I of the Arab Charter of Human Rights; and in Article 32 of the Human Rights Declaration of the Association of Southeast Asia Nations.⁶

Specifically, Article 15 of the ICESCR sets forth:

1. the right of everyone:
 - (a) To take part in cultural life;
 - (b) To enjoy the benefits of scientific progress and its applications;
 - (c) To benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for the conservation, the development and the diffusion of science and culture.
3. The States Parties to the present Covenant undertake to respect the freedom indispensable for scientific research and creative activity.
4. The States Parties to the present Covenant recognize the benefits to be derived from the encouragement and development of international contacts and co-operation in the scientific and cultural fields. (www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx)

This also means that citizens, all of us, are entitled to report specific violations of human rights, including those relating to science and the enjoyment of its benefits. The recognition of a human right is therefore also a call for mobilisation; it involves the acknowledgement of our responsibilities to check and strengthen the enjoyment of this right across the world.

It is obvious, and it will be obvious to the reader, that any area of scientific research needs to be regulated: clinical trials, the use of non-human animals in research, research on artificial intelligence and reproduction and so on are all regulated. Both financial constraints and regulations pose clear and inevitable limits to the freedom to perform scientific research. Knowledge transfer should be also regulated (as Rhodes persuasively argues in Chapter

6, this volume) because it is not always unproblematic. Freedom, thus, does not mean absence of regulation and lack of accountability. A serious ethical analysis of the various options, the advantages and disadvantages of various alternatives, the long-term consequences of scientific developments and innovations for future generations as well as for those living in other parts of the world, all needs to be part of dialogue on the regulation of research. This volume represents a contribution to this continued analysis. Although it is a small contribution, and certainly limited, I would like to stress the importance that enterprises such as these may bring to fruition by mentioning some of the achievements obtained through this forum.

The World Congress, together with fifty Nobel laureates who agreed to support the call, solicited the European Union to fund research involving embryonic stem cells. The 7th Framework Programme for Research and Technological Development was subsequently approved, which lifted the ban on the funding on embryonic stem cells, and thus now allows the funding of projects involving adult, induced pluripotent stem cells and embryonic stem cells, under special regulations and in accordance with national legislation. The World Congress also participated in action and consultation aimed at ensuring that this would continue in the 8th Framework Programme, now called Horizon 2020.

Another important achievement involved Costa Rica. In 2012 a hearing was held at the Inter-American Court of Human Rights concerning Costa Rican law which prohibited *in vitro* fertilisation. Two doctors from Costa Rica participated in one of the national meetings of the World Congress. The World Congress deposited a third-party judgment (*amicus curiae*) in defence of people's reproductive rights, highlighting the discriminatory nature of the law in question and its incompatibility with the fundamental human right to found a family.⁷ Also as a result of the third-party intervention submitted by the World Congress, the courts condemned Costa Rica's legislation, which was consequently abrogated.

The World Congress for Freedom of Scientific Research has also presented or supported various petitions to the European Parliament, on euthanasia, HIV and reproductive and sexual health. The World Congress took an active role in the case of *Costa and Pavan v. Italy*. This case concerned a man and a woman in a relationship, both carriers of the gene for cystic fibrosis, who were denied access to pre-implantation genetic diagnosis under the Italian Law 40 on assisted fertilisation.⁸ The World Congress submitted an *amicus curiae* with various patients' coalitions and sixty MPs. On 28 August 2012 the European Court of Human Rights condemned Italy for violation of Article 8 (right to respect for private and family life) of the European Convention on Human Rights.

The World Congress has, between 2016 and 2017, repeatedly denounced to the United Nations the repressive policies adopted in the Philippines by Rodrigo Duterte, under the guise of the 'war on drugs'. As may be known, the anti-drug hard line taken by Duterte hits the poorest sections of society,

and has resulted in the killing of over 8,000 people. Representatives of the World Congress participated and presented evidence at the 60th session of the UN Commission on Narcotic Drugs held in Vienna in March 2017, also in support of the vice-president of the Philippines, Maria Leonor Giorna Robredo, who has repeatedly intervened to denounce the massacre operated by Duterte in the name of the war on drugs.

These actions and achievements are important, as they illustrate the value of coordinated work between democratic states for the active consolidation of human, civil and political rights worldwide. Moreover, they also illustrate that the activation of international jurisdictions can guarantee supranational protection of democratic rights. Forums such as the World Congress ensure that debates do not remain confined to the 'ivory tower' of 'armchair academics', or within specific disciplines, or within specific ideological alliances, but can result in practical and political initiatives that remain sensitive to cultural identities.

The main message that this volume wants to convey is that science, research, development and the protection of the human, civil and political rights of many of us depend on the cooperation of many: scientists and policymakers of course, but also academics and lay citizens. Scientific development also depends on continued dialogue with all political parties; it involves popular action at national and international levels, consultations, knowledge transfer and, it is important to stress, non-violent action. Strong ideological opposition in delicate areas such as embryo research, narcotic drug use, women's health (fertility treatments of various kinds) has fomented, as is sadly well known, episodes of serious violence. This book stresses the importance of dialogue and non-violent mobilisation.

This volume is perhaps only a small contribution to the international debate on freedom of scientific research, and there are many areas of science that we have not considered – and many ideas about regulation that we have not explored. But we hope that it will provide a method of cultural exchange, give some interesting perspectives and stimulate further debates on issues relating to science, freedom of research and individual rights and responsibilities.

Notes

- 1 www.un.org/en/universal-declaration-human-rights (last accessed 26 October 2017).
- 2 www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx (last accessed 26 October 2017).
- 3 www.europarl.europa.eu/charter/pdf/text_en.pdf (last accessed 26 October 2017).
- 4 www.narf.org/wordpress/wp-content/uploads/2015/09/2016oas-declaration-indigenous-people.pdf (last accessed 26 October 2017).
- 5 www.oas.org/juridico/english/treaties/a-52.html (last accessed 26 October 2017).
- 6 www.asean.org/storage/images/ASEAN_RTK_2014/6_AHRD_Booklet.pdf (last accessed 26 October 2017).

- 7 www.associazionelucacoscioni.it/wp-content/uploads/2012/11/atto-Definitivo-intervento-paginado-traducido-4_.pdf (last accessed 26 October 2017).
- 8 See official documents at <https://strasbourgobservers.com/category/cases/costa-and-pavan-v-italy> (last accessed 26 October 2017).

Reference

Giordano, S., Coggon, J., and Cappato, M. (eds) (2012), *Scientific Freedom*, London: Bloomsbury.