Book of abstracts

THE RIGHT TO ENJOY THE BENEFITS OF SCIENCE

6TH MEETING
ADDIS ABABA
25-26|02|2020

WORLD CONGRESS FOR FREEDOM OF SCIENTIFIC RESEARCH

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This book presents the abstracts and proceedings of the 6th meeting of the **World Congress for Freedom of Scientific Research** co-organised by **Associazione Luca Coscioni**, **Science for Democracy** and the **African Union**. The Congress took place in Addis Ababa, Ethiopia, on 25 and 26 February 2020.
The book was edited by Ms. Giulia Perrone, Board Member of Associazione Luca Coscioni and Member of Science for Democracy.

The video-recording of the Congress is available at the following links:

Opening session 1/2:
www.facebook.com/science4dem/videos/491196998457059

Opening session 2/2:
www.facebook.com/science4dem/videos/201013494614487

Session 1:
www.facebook.com/science4dem/videos/511651023064029

Session 2:
www.facebook.com/science4dem/videos/874617152997177

Session 3 part 1/3:
www.facebook.com/science4dem/videos/268695387430478

Session 3, part 2/3:
www.facebook.com/science4dem/videos/1488816181273031

Session 3, part 3/3:
www.facebook.com/science4dem/videos/1111051459236130

Session 4, part 1/2:
www.facebook.com/science4dem/videos/234550214243157

Session 4, part 2/2:
www.facebook.com/science4dem/videos/181369159828977

Closing session and adoption of final recommendations:
www.facebook.com/science4dem/videos/935603660192196

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or contact us at: **info@sciencefordemocracy.org**

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CONCEPT NOTE

THE RIGHT TO ENJOY THE BENEFITS OF SCIENCE

The 6th meeting of the **World Congress for Freedom of Scientific Research** was organized by **Associazione Luca Coscioni** and **Science for Democracy**. The event took place on 25th and 26th February at the African Union Commission and it was co-sponsored by the AU Commission in the person of Sarah Mbi Enow Anyang Agbor, Commissioner for Science and Technology.

The interaction between science, the scientific method, evidence-based debates and the decision-making process in full respect of the international Rule of Law has always been at the center of the five meetings of the **World Congress** organized since 2004 at the Italian and European Parliament by the Associazione Luca Coscioni.
The 2020 Congress was convened in a moment in which a group of experts of the United Nations was finalizing a "General Comment" on Article 15 of the International Covenant on Economic Social and Cultural Rights (ICESCR), aimed at defining the so-called "right of" and the "right to" science.

> **Article 15**
> 1. The States Parties to the present Covenant recognize 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.[1]

The "General Comment" was formally adopted at the 67th session of the UN Committee on Economic, Social and Cultural Rights, which took place in Geneva right after the Addis

[1] UNGA, *International Covenant on Economic, Social and Cultural Rights*, 16 December 1966, available at: www.ohchr.org/en/professionalinterest/pages/cescr.aspx.

gathering[2]. The document serves as the basis for all State parties to effectively respect, protect and fulfil the right to science and to submit their report on the implementation of the right to science, in compliance with the guidelines provided by the UN Committee on Economic, Social and Cultural Rights.
The Addis Congress addressed the ramifications of the "right of" and the "right to" science on a variety of topics that are becoming crucial for African countries to pursue the Sustainable Development Goals (SDG) by 2030[3], arguing that international legality will need to take into structural consideration all issues related to scientific evidence when policy or judicial decisions are taken and stressing the need to educate the general public on the ways in which science works through the verification, duplication, and falsification of research. All SDGs would greatly benefit from investments in research and technology to strengthening science and innovation in the developing world, where the need to balance the principle of precaution with the innovations produced by research should become a topic for academic, political and public debate.

The decision to organize the 6th session of the World Congress in Africa was taken at the European Parliament in Brussels in April 2018, at the end of the 5th meeting, when it was decided that the following World Congress meeting should "[...] **take place in a developing country that is struggling to establish or reinforce its democratic institutions, the Rule of Law and that is promoting and protecting scientific progress**"[4].

The preparation of the 6th meeting of the World Congress has provided an opportunity to reach out, *inter alia*, to the Commissioner of the African Union (AU), which has confirmed her interest in partnering with Science for Democracy and the Associazione Luca Coscioni to co-host the event at the AU headquarters in Addis Ababa, taking a particularly active role in reaching out to African players.
In several recent AU-sponsored meetings, science has been hailed as one of the resources that should be made increasingly available to the African continent both in terms of investments and policies that can allow its use in line with the **Agenda 2063**[5] launched to mark the 50th anniversary of the establishment of the African Union. The AU declaration outlining the agenda marked the re-dedication of Africa towards the attainment of the African vision of "**An integrated, prosperous and peaceful Africa, driven by its own citizens and representing a dynamic force in the international arena"**[6] to be achieved as a continental endeavor by 2063.

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[2] CESCR, General Comment No. 25 on Science and Economic, Social and Cultural Rights, available at: www.undocs.org/E/C.12/GC/25.

[3]About the Sustainable Development Goals: www.un.org/sustainabledevelopment/sustainable-development-goals/.

[4]Full text available at: www.freedomofresearch.org/final-declaration-of-the-5th-session-of-the-world-congress-for-freedom-of-scientific-research/.

[5] African Union, *Agenda 2063 - The Africa We Want,* available at: www.au.int/en/agenda2063/overview.

[6] African Union, 50th Anniversary Solemn Declaration, available at: www.au.int/sites/default/files/documents/36205-doc-50th_anniversary_solemn_declaration_en.pdf.

Among the scientific keynote speakers, the Congress saw the participation of **Professor Richard J. Roberts,** 1993 Nobel Prize in Physiology or Medicine, **a**nd **Professor Michele De Luca**, Director, Centre for Regenerative Medicine "Stefano Ferrari", University of Modena and Reggio Emilia, Modena, Italy. The **Vice-Minister of Foreign Affairs and International Cooperation Emanuela Del Re** sent a video-message stressing the interest of Italy in promoting and advancing the right to science both at national and international level. **UNESCO** also participated in the Congress and the adoption of the final recommendations.

Participants in the World Congress included **representatives from national executive and legislative bodies, relevant regional organizations and UN system, academics and research institutes, media, civil society and non-governmental organizations with a particular focus on those that work on patients rights.**

In preparation to the Congress, on 11 November 2019 Associazione Luca Coscioni and Science for Democracy, in partnership with the Addis Ababa University (Department of Law) and the University of Turin, held the legal seminar "**Advancing Knowledge-led Development Through The Right to Science in Africa**"[7] that took place at the Addis Ababa University. The seminar saw the participation of both local and international academics and experts in the field of science and human rights.

[7]The video recording of the symposium is available at: www.sciencefordemocracy.org/symposium-advancing-knowledge-led-development-through-the-right-to-science-in-africa/.

PROGRAM

DATE: 25-26 February 2020
LOCATION: Addis Ababa, African Union Commission, Plenary Old Building

TUESDAY, 25 FEBRUARY 2020

08:00 REGISTRATION AND WELCOME COFFEE

09:00 OPENING SESSION

Master of Ceremony:

Marco Perduca, *Co-founder and coordinator, Science for Democracy, former Senator*

Opening remarks:

H.E. Sarah Mbi Enow Anyang, *Commissioner for Human Resources, Science and Technology* of the *African Union*

Filomena Gallo, *Secretary general, Associazione Luca Coscioni*

Photo Opportunity and Coffee Break

Emanuela Del Re, Vice-Minister of Foreign Affairs and International Cooperation, Italy (video-message)

Angela Melo, Director, Policies and Programmes, UNESCO (video-message)

Mikel Mancisidor, Adjunct Associate Professor of Law, Washington college of Law, UN Treaty Body Expert at CESCR, co-drafter of the General Comment on article 15 ICESCR (via Skype)

Lectio Magistralis: *Scientific Research is key to future development*
Sir Richard John Roberts, Nobel Prize in Physiology, Chief Scientific Officer, New England Biolabs

LUNCH BREAK

14:00 1ST SESSION: *THE BENEFITS OF STEM CELLS RESEARCH AND GENOME EDITING FOR HUMAN HEALTH*

Facilitator: **Marco Cappato,** *Co-founder, Science for Democracy; Treasurer Associazione Luca Coscioni, former MEP*

Stem cells: facts, hopes, hoaxes and hurdles

Michele De Luca, Full Professor of Biochemistry, Director of the Centre for Regenerative Medicine "Stefano Ferrari", University of Modena and Reggio Emilia, Modena, Italy

How we can use stem cells to repair the brain
Malin Parmar, Professor at Developmental and Regenerative Neurobiology, Lund University, Sweden

The London Project to Cure Blindness at 10 years, have we found a cure?
Pete Coffey, Professor of Visual Psychophysics, Institute of Ophthalmology Faculty of Brain Sciences, University College London, United Kingdom

Genetic services for rare disorders in Egypt and obstacles that scientists encounter
Ghada El Kamah, Professor of Clinical Genetics, Coordinator of the Hereditary Blood Disorders and Genodermatoses Clinics and Research Teams, Human Genetics and Genome Research Division, National Research Centre, Cairo, Egypt

15:30 COFFEE BREAK

15:45 2ND SESSION: *THE BENEFITS OF EVIDENCE-BASED POLICIES TO ADVANCE SEXUAL AND REPRODUCTIVE RIGHTS*

Facilitator: Pia Locatelli, former MP and MEP, former Member of the IPU Advisory Group on HIV/AIDS and Maternal, Newborn and Child Health (MNCH) (later renamed: IPU Advisory Group on Health)

Hon. Dr Christopher Kalila, MP Zambia; Hon. Dr Ouattara Bakary, MP Côte d'Ivoire; Hon. Aboubakry Ngaide, MP Senegal; Hon. Mwakibete Fredy Atupele, MP Tanzania

Overpopulation and voluntary family planning, setting a new political agenda
Michele Usuelli, Regional Councillor of Lombardia, +Europa con Emma Bonino; MD neonatologist; Partnership for Maternal Neonatal and Child Health: focal point for Italian Society of Neonatology

The importance of evidence in policy making
Consolata Opiyo, Vice Chair, International Community of Women Living with HIV Eastern Africa

Maternal and Child Health at the Center of the Continuum of Care: the Experience of Doctors with Africa CUAMM
Michele d'Alessandro, International Relations Office of Doctors with Africa CUAMM

18:30 DINNER AT THE AFRICAN UNION (MULTIPURPOSE ROOM, NEW BUILDING)

WEDNESDAY 26 FEBRUARY

08:00 REGISTRATION AND WELCOME COFFEE

09:00 3RD SESSION: *THE BENEFITS OF SCIENTIFIC INNOVATIONS IN THE FARMING AND CONSUMER GOODS SECTOR*

Facilitators: Vittoria Brambilla, PhD, Department of Agricultural and Environmental Sciences, University of Milan, Italy; and *Marco Perduca*

The Nobel Laureate campaign supporting GMOs
Sir Richard John Roberts, Nobel Prize in Physiology, Chief Scientific Officer, New England Biolabs

Communicating the Science of Gene Modification: Past, Present and the Future
Margaret Karembu, Director of ISAAA AfriCenter, chair of the Open Forum on Agricultural Biotechnology (OFAB) Kenya Chapter Programming Committee

Genome editing for agriculture: a global overview
Marc Heijde, PhD, VIB-International Plant Biotechnology Outreach

The Evolving Space and Emerging Key Niches for Modern Breeding in Africa
Emmanuel Okogbenin, Director, Programme Development and Commercialization (AATF)

11:00 COFFEE BREAK

Tobacco Harm Reduction in South Africa: Perceptions on alternative nicotine delivery products
Solomon Tshimong Rataemane, MD, South Africa Member, Medical and Scientific Advisory Board PharmaCielo

Tobacco harm reduction: scientific bases and rationals
Fares Mili, Chairman of the Tunisian Society of Tobaccology and Addictive Behaviors

Recognizing the Right to Information and the Right to Science: A Path to Realizing the Right to Health in Lower Middle-Income Countries
Tequila Bester, Programme Coordinator for Human Rights, Vulnerable Persons, and other Social Issues at The Association for International Human Rights Reporting Standards

12:45 LUNCH BREAK

14:00 4TH SESSION: *THE BENEFITS OF AN OPEN (ACCESS TO) SCIENCE, DATA AND ARTIFICIAL INTELLIGENCE*

Facilitator: Federico Binda, Co-Founder, Science for Democracy and Dpt. of Mathematics, University of Milan

Open science for all: building a global consensus on real access to science
Norman Mushabe, Science Programme Consultant at the UNESCO Liaison Office to the African Union and the United Nations Economic Commission for Africa in Addis Ababa, Ethiopia

Open Science vs Intellectual Property in a Democratic Order

Roberto Caso, Associate Professor, Private Comparative Law, University of Trento

Digital Literacy Brings Freedom of Research – Ethiopian Experience
Margareth Gfrerer, Higher Education Strategy Center, Ethiopia

The benefits of open science: an African perspective
Solomon Mekonnen, National Open Access Coordinator, Addis Ababa University and EIFL

16:00 COFFEE BREAK

16:15 PRESENTATION AND ADOPTION OF FINAL RECOMMENDATIONS

16:45 CLOSING REMARKS

17.15 SHUTTLE BACK TO SKYLIGHT HOTEL

19:00 DINNER AT HABESHA 2000 RESTAURANT (NEW LOCATION)

OPENING REMARKS

THE HUMAN RIGHT TO SCIENCE

Video-message from the Vice-Minister of Foreign Affairs and International Cooperation Emanuela Del Re at the opening of the World Congress for Freedom of Scientific Research in Addis Ababa, Ethiopia, 25th February 2020

Dear Friends,

I feel honoured to address the sixth meeting of the World Congress for Freedom of Scientific Research, a very important initiative organized by Associazione Luca Coscioni and Science for Democracy.

The Italian Ministry of Foreign Affairs have a very close relationship with Associazione Luca Coscioni. We have been cooperating for a long time, especially within UN events, to foster the discussion on the links between scientific research and human rights.

This Congress is crucial to promote the debate on the scope and possible implications of the so-called "right to science", especially after the publication of the General Comment prepared by the UN Committee on Economic, Social and Cultural Rights on this particular issue.

Pillars of this remarkable endeavor that does mark the perimeter of the discussion are two articles in particular. Article 27 of the Universal Declaration of Human Rights stating "Everyone has the right to freely participate in the cultural life of the community" and "the right to enjoy the arts and to share in scientific advancement and its benefits". Article 15 of the International Covenant on Economic, Social and Cultural Rights clarifying that States Parties recognize "the right of everyone to enjoy the benefits of scientific progress and its applications".

Science has a very important impact on almost every aspect of human life. It is a very powerful tool for advancing human development, but we also need to raise awareness on possible negative impacts scientific development and technology might have on the enjoyment of human rights.

The right to benefit from scientific progress implies both freedoms, such as the right to participate in scientific progress and freedom of scientific research, and entitlements, such as the right to enjoy the benefits of scientific progress. It also contains obligations, including the duty of all States to combat and prevent any discrimination in the design and implementation of all policies related to science.

The choice to host the sixth edition of the Congress in Africa, in Addis Ababa, in cooperation with the African Union, is very significant as it allows the movement of ideas and the involvement of more and more African governments, researchers and practitioners in this discussion. Our common challenge consists in bringing benefits of scientific research to the whole planet, especially to developing countries. Through scientific progress, we can also address new threats such as climate change and desertification, thus contributing to the achievement of Agenda 2030 on Sustainable Development Goals.

We must also remember that women still account for less than a third of the scientific research community. Of course, women must not be left behind in the pursuit of progress and in the enjoyment of benefits from scientific research. Increasing women's participation in scientific studies and scientific research is crucial. I hope this will be one of the main topics of your discussion.

Unfortunately, I will not be able to participate as I have institutional commitments, but I will follow the discussion with great interest.

I really wish you all efforts for discussion and hopefully even more follow up in the future. Thank you very much.

OPENING REMARKS

THE RIGHT TO SCIENCE AND SUSTAINABLE DEVELOPMENT GOALS

Video-message from the Director of Policies and Programmes (UNESCO) Angela Melo at the opening of the World Congress for Freedom of Scientific Research in Addis Ababa, Ethiopia, 25th February 2020

Your Excellencies,
Ladies and Gentlemen,

Since the mid-1980s, UNESCO has hosted intense debates on the values that should regulate and guide high-quality research and innovation for our developing societies.

Only recently is a consensus among states on human rights and ethics coalescing around a precise set of international norms – that governments have agreed should be valid for all science, everywhere.

The United Nations family of organizations represents and carries forward this message from these assembled governments, representing a global normative agreement.

It is timely today that this meeting examines this human rights aspect, because this is so important to achieving sustainable development.

- There is inequality in access to – and in creation of – scientific knowledge, and insufficient problem-solving capacities right here in the African community of states. Science, technology and innovation are needed.
- There is an unprecedented number of young people seeking access to higher learning through university education, and some, once qualified, are leaving to be scientists elsewhere.

Human rights principles such as equality and non-discrimination are not enough: we need to put into practice the **right to science**.

The linkages between this and sustainable development are widely accepted: in the **2030 Agenda for Sustainable Development,** no less than twenty-three targets explicitly mention science, technology and innovation.

Allow me therefore to express appreciation and draw your attention to:

- Ongoing work at the Committee on Economic Social and Cultural Rights that will result in a general comment on science as a human right this year;
- Already in 2017, 195 states at UNESCO concluded on the legal standards for its operationalization, in a text called the Recommendation on Science and Scientific Researchers; and

- 2020 will be the first time ever that states are required to monitor their application of the human right to science.

Monitoring of the human right to science is not a simple matter: it will help if science communities engage in 2020 so as to give the human right to science real applications in-countries and to make this first time a real benchmarking exercise.

Driven by digitalization and globalization, scientific collaborations could better engage our African communities and to allow that "scientific and technological knowledge and its potentialities be promptly geared to the benefit of all peoples" (in the words of the Recommendation on Science).

There is also ongoing work on technology sharing, Open Science, and Open Educational Resources, all of which may catalyze actions for fulfilling the **human right to science** and **bridging the science, technology and innovation gaps** between and within countries.

Starting today, I will be inviting that the African Union as a whole consider endorsing the Recommendation on Science and Scientific Researchers, which has in practical terms already been endorsed by the European Union, and I ask that governments monitor their application of the right to science.

Further, I invite each and every one present at this conference to capture and affirm this right to science as an imperative of social justice and of sustainable development.

At the frontiers of countries, it is by respecting accepted international norms that we will encourage and participate in global science favoring sustainable development.

Thank you for your attention and I wish the conference every success!

OPENING REMARKS

TOWARDS THE GENERAL COMMENT ON SCIENCE

Speech delivered in his personal capacity at the opening of the World Congress for Freedom of Scientific Research in Addis Ababa, Ethiopia, 25th February 2020 by Prof. Dr. Mikel Mancisidor, member of the Committee on Economic, Social and Cultural Rights

Good morning everyone.
First I want to thank the Luca Coscioni Associazione for having invited me to this extremely important meeting. I sincerely admire the pioneering work this Associazione is doing on the relationship between science, freedom, human dignity and human rights. The impact of their activities has become universal and now they are perhaps the civil society organization with the most effective global impact on the Human Right to Science.
It's an honour for me to be here to share with you my views on the human right to science. It's the first time I have the opportunity to talk on this topic in Africa, and let me be candid: I'm excited. I'm very sorry not to be in person in Addis Ababa with you as I had actually wished, but I'm now here in Geneva attending the sessions of the Committee on Economic, Social and Cultural Rights of which I am a member. This same week we'll have two sessions, tomorrow and on Thursday, to discuss and negotiate the last draft of a new General Comment on Science and Economic, Social and Cultural Rights known by many, in an informal way, as the General Comment on the Human Right to Science. What is this General Comment about? What is a General Comment and why is it so important? And more importantly what is the Human Right to Science? These are the questions I'd like to present to you today.
I have been given 20 minutes and, in order to make the most of it, I plan to organize my presentation in four parts: first, a brief history of the Human Right to Science; second, what are we doing now at the UN in this respect; third, some ideas about the normative content of the Human Right to Science, in other words, what is this right about; and finally a call to all of you to take part in this global challenge that this Human Right to Science raises.

First, on history. It's important to understand the historical context in which the Universal Declaration of Human Rights was negotiated during 1947 and 1948. The two atomic bombs dropped on Hiroshima and Nagasaki in August 1945 raised the issue of the power of science, its limits, its control and the social responsibility of the scientists. In 1947 the Nuremberg Trial of the Doctors showed the most horrendous evidence and the 7 defendants found guilty were given the death penalty right in the middle of the negotiation process for the Declaration. René Cassin, considered one of the major fathers of the Universal Declaration, said that that news "influenced the debate on how or whether to connect human rights and science in the Universal Declaration".
During the negotiation process on the Declaration, chaired by Eleanor Roosevelt, the formulation went from the initial version that underlined "the benefits that result from scientific discoveries" to the wider idea of the right to "share in scientific advancement".

Some delegates, for example the Chilean member, considered that “not everyone was sufficiently gifted to play a part in scientific advancement" and that what was needed was for the text to state that everyone has the right "to share in the benefits that result from scientific advancement".
But other members, the Chinese and the Lebanese delegates replied that even if one does not have scientific knowledge we all have the capacity for certain enjoyment of science which goes beyond just its direct benefits.
Both ideas, the concept of participation and the idea about benefits of science were both included in the final version of the Universal Declaration: “everyone has the right freely (…) to share in scientific advancement and its benefits”. The word “share” here although it may appear in general at first sight as less “active” than "participate" or "take part", but indicates an idea of action or agency, an idea of active participation in the scientific enterprise, and must therefore be considered to have the same meaning as “participate” or “take part” used in the other versions of the Declaration, all of them equally official.
Perhaps this is the most important idea I have to share with you this morning: that the Universal Declaration described a right with two components, first, the right to take part in science and second, the right to benefit from its applications.
The Universal Declaration included these scientific issues inside the article devoted to cultural rights. This is important, this means that science in not just a means, a tool, an instrument for the enjoyment of other rights (for example, the right to health), as important as it is, but it’s also a human right in itself (the right to ask, to know, to study, to discuss, to research, to understand, to wonder, even the right to enjoy the beauty of science, quoting the Chinese member. In conclusion: a cultural right).

Second part of my lecture: what are we doing now at the UN in this respect?
After the Declaration, the UN approved two covenants to develop the International Human Rights Law. Scientific issues were included in the Covenant of Economic, Social and Cultural Rights, again, of course, in the article devoted to cultural rights. The Committee on Economic, Social and Cultural Rights, the supervisor of this Covenant, decided a few years ago to update this right by means of a General Comment. I was appointed as rapporteur for this General Comment and from the last two years together with another member co-rapporteur, Rodrigo Uprimny, from Colombia.
What is a General Comment? The short answer is that a General Comment is the authoritative interpretation made by a UN Committee of the meaning and the extent of a human right included in a treaty. That means that the committee explains to the states what their obligations are according to the treaty. A General Comment can’t create a new obligation for a state but can and should remind the states in an up to date way what it committed to do, in a binding or compulsory manner, on the day it ratified the Covenant. That’s why the General Comment is so powerful: because it is an authoritative interpretation for 170 states party to the treaty, including 41 countries from Africa.
The Committee will study tomorrow, on Thursday and next week the last draft and the comments proposed by more than 70 countries and organizations, like for example Luca Coscioni Associazione. I hope and desire with all my heart that in 10 days this General Comment will be approved. This General Comment would, in this way, assist States Parties in the implementation of the rights of the Covenant related to science and also provide guidance to the United Nations, Human Rights organisations, scientific organisations, universities and

scientists, as well as civil society as a whole, including corporations, to have a better understanding of their rights and obligations in relation to science.

Third point. And what will the content of the General Comment be? Until the moment when the General Comment will be officially approved I'm not able to assure what the content will be, but I can, in my personal capacity, share with you some important ideas:
The General Comment understanding of science is based on that adopted by UNESCO in its 2017 "Recommendation on Science and Scientific Researchers". Science therefore means "a complex of knowledge, fact and hypothesis, in which the theoretical element is capable of being validated in the short or long term, and to that extent includes the sciences concerned with social facts and phenomena".
Thus, science, including natural and social sciences, refers both to a process following a certain methodology (doing science) and to the results of this process (knowledge, applications). It's true that other forms of knowledge may claim protection and promotion as a cultural right, but knowledge should only be considered as science if it is based on critical inquiry and open to falsifiability and testability. Knowledge which is only based on tradition or revelation or authority, without the possible contrast with reason and experience, or which is immune to any falsifiability or intersubjective verification, cannot be considered science.
What does "benefits" mean in the context of this General Comment? The term "benefits" refers here first to the material results of scientific research, such as medicines, vaccination, technological instruments and so on. Secondly, benefits refer to the scientific knowledge and information directly deriving from scientific activity, because Science provides benefits not only because of its material results but also through the development and dissemination of the knowledge itself. And finally, benefits also refers to science's role in forming critical and responsible citizens who are able to participate fully in a democratic society,
We are not interested in an approach according to which only scientists would have a right to participate in science and contribute to scientific development and, on the other hand, the general population would merely have the right to enjoy in a passive manner the benefits of scientific progress and its applications. Doing science and scientific policies does not only concern scientific professionals but also includes citizen science (that means, ordinary people doing science) and the dissemination of scientific knowledge. State Parties must not only refrain from preventing citizen participation in scientific activities but must also facilitate such participation.
Science also requires, according to the Covenant, a strong protection of freedom of research. Therefore the Covenant establishes a specific duty for States to "respect the freedom indispensable for scientific research". This freedom includes at least the following dimensions: the protection of researchers from non-justified interventions; their possibility to contribute to the definition of the aims and objectives of the research; the possibility to express freely and openly on the ethical, human, scientific, social or ecological value of certain projects; the possibility of researchers cooperating with other researchers nationally and internationally; and the sharing of scientific data between researchers, with policymakers, and with the public wherever possible. However, freedom of scientific research is not absolute; some limitations are, as is the case for every other human right, possible but only in certain well defined cases and conditions: "the right will only be subject to such limitations – says the Covenant – as are

determined by law only insofar as this is compatible with the rest of the rights, and only for the purpose of promoting the general welfare in a democratic society".
Finally, according to the Covenant, all States have a general duty to cooperate internationally but this duty is reinforced in the case of scientific activities: States shall recognize the benefits "derived from the development of international contacts and co-operation in the scientific and cultural fields". States should take all measures necessary to enable scientific researchers to participate in the "international scientific and technological community", especially through facilitating their travel in and out of their territory. Developed States should contribute to the development of science and technology in developing countries. Benefits resulting from any research and its applications should be shared with the international community. In addition international cooperation is essential because the most important risks related to science and technology, such as climate change, dangerous technologies, weapons of mass destruction, or the risks of pandemics, like the coronavirus these days, needs States to promote multilateral agreements to prevent these risks.
Much more issues are included in this General Comment, but because of the limitation of time I'll stop here inviting you to have a more close look at the draft you have been provided with in this conference.
To sum up, hopefully this will be a General Comment that will present a right to benefit, to access and to participate; a right fostering the conservation, development and diffusion of science and technology; a right which implies freedoms; and a right with a strong international cooperation component.
The last paragraph, in the last draft, of the General Comment might be read as a conclusion
"This set of rights, entitlements, liberties, duties or obligations related to science, analyzed in this General Comment, might be bring together in a single broad concept named the human right to science, in the same way that, for example, the human right to health encompasses a set of rights and freedoms. This approach and name has already been adopted by the Special Rapporteur on Cultural Rights, by UNESCO, by some international conferences and summits and by some important scientific organizations and publications".
I invite, dear colleagues, this Congress and the African Union to join this global movement for the Human Right to Science of which Luca Coscioni Associazione is one the greatest champions.

And that brings us to the next and last point. If the General Comment is approved next week this will represent a new stage. A General Comment can't be understood as the end of any process but an extremely important turning point. We'll have a new and powerful legal instrument for the promotion of science in the service of humanity, in the service of those in need, in the service of a more prosperous and fair life for people in need. But it'll be a useful tool only if it's known and used by all of you. The approval of this General Comment will mark in this sense a new starting point and I invite all of you to take part in it.
Only if it's known, subject of social diffusion and used when needed, will the General Comment on science provide people and the scientists with powerful legal and political tools to participate in the scientific enterprise, to better understand the importance of science in a democratic society, for better access to scientific knowledge and its application, to better share the basic knowledge and to better cooperate internationally around the world.
Thank you very much and I wish you the greatest success in this congress.

ABSTRACTS

SCIENTIFIC RESEARCH IS KEY TO FUTURE DEVELOPMENT

Richard J. Roberts, Chief Scientific Officer, New England Biolabs

The health and wealth of the world is increasingly tied to advances in science. Nowhere is this more apparent than here in Africa, where the availability of nutritious food is an urgent problem as the population increases. Biotechnology can play a key role here, but this is also an area where politicians need to become involved in making sure that modern methods are encouraged and not over-regulated. Another product of science is the ubiquitous presence of cell phones, which are not without their own problems. Contrasting rules and regulations for these two activities illustrate a problem faced by politicians, who are usually untrained and often disinterested in science. This leads to the final point I will make, which concerns education, not just in science, but more generally. An educated populace, both lay people and the elite in society, is key to both advancing scientific research and making the most of the discoveries made.

HOW WE CAN USE STEM CELLS TO REPAIR THE BRAIN

Malin Parmar, Professor in Cellular Neuroscience, Lund University

New neurons are only formed in a few discrete regions within the adult human brain and its ability to self-repair after disease or injury is therefore very limited. My studies aim to achieve cell replacement and functional brain repair with focus on Parkinson's Disease (PD), which is a common neurodegenerative disorder for which there is currently no cure. Stem cell technologies have the potential to be at the forefront of new treatments and the field is rapidly developing.

THE LONDON PROJECT TO CURE BLINDNESS AT 10 YEARS, HAVE WE FOUND A CURE?

Pete Coffey, Professor of Visual Psychophysics, Institute of Ophthalmology, Faculty of Brain Sciences, University College London, United Kingdom

The London Project to Cure Blindness is a collaboration between Professor Pete Coffey and Dr Lyndon da Cruz from University College London and Moorfields Eye Hospital. The project aims to use Stem Cell technology to restore sight, prevent progression and ultimately improve the quality of life for patients with Age-Related Macular Degeneration (AMD) and other retinal and macular disorders, combining cutting edge knowledge and technology from the laboratory, clinic and operating theatre.

SITUATION AND PROBLEMS MET IN GENETIC RESEARCH IN AFRICAN DEVELOPING COUNTRIES: EGYPT AS AN EXAMPLE

Ghada El Kamah, Professor of Clinical Genetics, Coordinator of the Hereditary Blood Disorders and Genodermatoses Clinics and Research Teams, Human Genetics and Genome Research Division, National Research Centre, Cairo, Egypt.

Developing countries have many limitations on the luxury of basic research and, research facilities are always directed towards applied science. Available means are usually directed to solve available needs and problems, Genetic services included. The presentation will elaborate on examples of past and current models within different genetics teams and health providers in Egypt specially the Human Genetics and Genome Research Division team at the National

Research Centre as the Hub for Human Genetics in Egypt, as well as the current situation and plans for more omics involvement in health services to avoid genomic divide.

OVERPOPULATION AND VOLUNTARY FAMILY PLANNING, SETTING A NEW POLITICAL AGENDA

Michele Usuelli, Regional Councillor of Lombardia, +Europa con Emma Bonino, MD neonatologist, Partnership for Maternal Neonatal and Child Health: focal point for Italian Society of Neonatology

214 million women in developing regions unmet need for FP according to WHO and UNFPA. Meeting this unmet need would result in a 75% decline in unintended pregnancies, unplanned births and induced abortions. Providing full contraceptive and maternal and newborn care would reduce annual maternal deaths from 308,000 to 84,000 and newborn deaths from 2.7 million to 538,000. Universal access to family planning is a human right, central to gender equality and women's empowerment. Through the fulfillment of this human right, we can contribute to harness demographic dividend, reduce the population bombs and improve the climate change.

THE IMPORTANCE OF EVIDENCE IN POLICY MAKING

Consolata Opiyo, Vice Chair, International Community of Women Living with HIV Eastern Africa

Using evidence to inform policy is not a new idea, what is clear from the literature is that policy should be informed from a wide breadth of Evidence. Key issues must include quality, credibility and relevance. Evidence based policies play a critical role in women-centered initiatives. The presentations will explain and point out if Kenya as a country has used evidence in its policy making process. How is evidence important in Policy Making?

MATERNAL AND CHILD HEALTH AT THE CENTER OF THE CONTINUUM OF CARE: THE EXPERIENCE OF DOCTORS WITH AFRICA CUAMM

Michele d'Alessandro, International Relations Office of Doctors with Africa CUAMM

This presentation gives an overview of the work of Doctors with Africa CUAMM in 8 sub-Saharan African countries. CUAMM's action focuses on health system strengthening and targets the weakest population groups, particularly women and children. CUAMM also carries out capacity-building activities and conducts and disseminates scientific research, with the ultimate goal of ensuring that the fundamental human right to health can be enjoyed by everyone everywhere.

THE NOBEL LAUREATE CAMPAIGN SUPPORTING GMOS

Richard J. Roberts, Chief Scientific Officer, New England Biolabs

When Monsanto first tried to introduce GMO seeds into Europe there was a backlash by the Green parties and their political allies, who feared that American agri-business was about to take over their food supply. Thus began a massive campaign not against the true targets, Monsanto and the large agri-businesses, but rather against the surrogate target, GMOs. This has had disastrous consequences for one of the most promising technologies ever developed for improving food supplies. I am spearheading a campaign by the Nobel Laureates to counter the damage that is being done to the poor people in this world – notably in the developing countries – by Greenpeace and their allies who have deliberately ignored the science that underpins GMOs

and have been painting horrific pictures of the dangers that might ensue. I will use Golden Rice as a clear example of the costs of these shortsighted policies.
Millions of children have died or suffered developmental impairment because of a lack of Vitamin A in their diet. Golden Rice could reverse this, but has become a target of the Green parties because it is a GMO. This is foolish and dangerous. How many more children must die before this is considered a crime against humanity? I will argue that the Pope and the major religious organizations in this world could play a pivotal role in countering the pseudoscience being propagated by the so-called green parties and make a real difference to the lives of the poor in this world.

COMMUNICATING THE SCIENCE OF GENE MODIFICATION: PAST, PRESENT AND THE FUTURE

Margaret Karembu, Director of ISAAA AfriCenter, chair of the Open Forum on Agricultural Biotechnology (OFAB) Kenya Chapter Programming Committee

Any mention of "genes" and related applications evoke strong emotions and varied opinions. This is what characterized the GMO debate over last two decades leading to slow adoption especially in Africa. With rapid advancements in genetic engineering and daunting challenges of sustaining quality living and that of the planet, what lessons can inform how we communicate and engage stakeholders more effectively for fast-tracking diffusion of the much needed innovations? This presentation explores factors that caused serious communication blunders at introduction of modern biotechnology and recommends various interventions for enhancing trust and confidence with emerging biosciences. Most importantly, scientists can no longer sit back and watch pseudo-scientists boss the stage with misinformation about gene-related innovations.

GENOME EDITING FOR A SUSTAINABLE AFRICAN AGRICULTURE

Marc Heijde, PhD, VIB-International Plant Biotechnology Outreach

Africa has good potential to reap the benefits associated with modern agricultural biotechnology. Plant biotechnology and breeding represent an invaluable toolbox to face the challenges of African agriculture, such as food and nutrition security, environment protection, soil fertility, and crop adaptation to new climatic conditions. As Africa has only relatively recently adopted agricultural biotechnology, it has the opportunity to harness the immense knowledge gathered over the last two decades while avoiding some of the difficulties experienced by early adopters. High-level research and education systems together with a specific regulatory framework are critical elements in the development of sustainable biotechnology-based agriculture and industry.

THE EVOLVING SPACE AND EMERGING KEY NICHES FOR MODERN BREEDING IN AFRICA

Emmanuel Okogbenin, Director, Programme Development and Commercialization, African Agricultural Technology Foundation (AATF)

Africa is still contending with food and nutrition security for over 1 billion people. Breeding has been very instrumental to the substantial gains in agricultural productivity globally. While Crop genetic improvement has evolved with time, the new trending global challenges associated with climate change, undernourishment/malnutrition, environmental safety, and emerging pests/diseases has justified the need to explore new plant breeding techniques (NPBT) to improve

breeding efficiency for product development precision. Whereas, innovation is essential, even equally critical is the facilitation of enabling policies and regulatory environment required to deploy NPBT novel products to catalyze agricultural transformation agenda and agribusiness in Africa.

TOBACCO HARM REDUCTION: SCIENTIFIC BASES AND RATIONALS

Fares Mili, Chairman of the Tunisian Society of Tobaccology and Addictive Behaviors

Many smokers have big difficulties to quit smoking because of genetic vulnerabilities, specific traits of personality, psychiatric comorbidities and deletere socioeconomic conditions. Smoking is also an addiction behaviour associated to a brain damage, cerebral pathway impairment and a reward system dysregulation. Approved Tobacco dependence treatment is effective at best in 1 in 5 cases. As it is with other substance abuse, there is a niche for a harm reduction strategy for those who are unable or unwilling to quit smoking. Electronic cigarettes, heated tobacco and other nicotine delivery systems are a safer alternative that have already proven their efficacy, but they either need more regulation and studies to prove their long term safety use.

RECOGNIZING THE RIGHT TO INFORMATION AND THE RIGHT TO SCIENCE: A PATH TO REALIZING THE RIGHT TO HEALTH IN LOWER MIDDLE-INCOME COUNTRIES

Tequila V. Bester, M.S., J.D., Programme Coordinator for Human Rights, Vulnerable Persons, and other Social Issues at The Association for International Human Rights Reporting Standards

The right to health has long been enshrined in international human rights law and codified in many laws around the world. However, individuals and communities must first realize, at a minimum, their right to information and their right to enjoy the benefits of scientific progress and its applications. Through the lens of harm reduction, the speaker discusses what governments and businesses can do to ensure that the right to health is realized, particularly in low- and middle- income countries.

OPEN SCIENCE FOR ALL: BUILDING A GLOBAL CONSENSUS ON REAL ACCESS TO SCIENCE

Norman Mushabe, Science Programme Consultant at the UNESCO Liaison Office to the African Union and the United Nations Economic Commission for Africa

The presentation forms part of the congress debate on "The right to enjoy the benefits of science, an African perspective". The presentation initiates the discussion on the meaning, scope and opportunities of Open Science between policy makers and experts from governments, academia and the private sector among others and defines the key challenges and possible risks of Open Science with suggestions on how to overcome them. The outcomes of the discussion, following the presentation, further include a consensus among the Multistakeholder participants on the meaning, scope and opportunities of Open Science from the perspectives of academia, policy makers, legislators, youth and the private sector. Key challenges and possible risks of Open Science are also mapped with preliminary recommendations on how to best address them – with call on the UN to develop guidelines to assist Member States in sharing their efforts towards the implementation of the many aspects of the "right to science", – believing that its full enjoyment can structurally contribute to the achievement of the Sustainable Development

Goals and become a pillar for the future consolidation of the Africa Agenda 2063, that aims to deliver on Africa's goals for inclusive and sustainable development, unity, self-determination, freedom, progress and prosperity.

OPEN SCIENCE VS INTELLECTUAL PROPERTY IN A DEMOCRATIC ORDER

Roberto Caso, Associate Professor, Private Comparative Law, University of Trento

The evaluation of scientific research is based on data protected by secrecy and intellectual property (e.g., Elsevier Scopus or Clarivate Web of Science). While science has progressed thanks to public dialogue, the current evaluation system is centered on private control of information. This represents a fundamental shift from democratic to authoritarian science. Open Science may confront this change only if it is accepted as the heir, in the digital age, of the values and principles that public and democratic science has traditionally fostered in the age of printing, thus becoming the guardian of a democratic society.

DIGITAL LITERACY BRINGS FREEDOM OF RESEARCH - ETHIOPIAN EXPERIENCE

Margareth Gfrerer, Managing Director of Ethiopian Institute for Higher Education

Since 2017 Ethiopian researchers receive trainings in digital literacy. Data Carpentry (www.datacarpentry.org) curricula are used to teach the basics of coding. Data work and its visualisation enables researchers to draw their own conclusion out of any database. The National Academic Digital Repository of Ethiopia (NADRE) as researchers' gateway to data and information from around the globe is linked to open repositories such as OAI-MPH, OpenDOAR, ROAR or OpenAIRE. The Digital Object Identifiers (DOIs) and ORCID-ids (www.orcid.org) allow Ethiopian researchers to share their results while keeping ownership on their findings.

ABOUT THE SPEAKERS

MARCO PERDUCA

Co-Founder and Coordinator of Science for Democracy, Marco Perduca was a senator in Italy from 2008 to 2013, serving on the Foreign Affairs, Justice, and Human Rights committees. For 20 years, he has coordinated the activities of the Nonviolent Radical Party at the United Nations (UN) in New York, as well as in Geneva and Vienna, and has organized high-level meetings to abolish the death penalty in Africa and Central Asia. He has also collaborated with British law firms and various American foundations on ending human rights violations in Italy. Mr. Perduca is an expert on UN mechanisms, with an emphasis on drug policy reform. When he was in Parliament, he was often a guest on the BBC as a commentator on Italian politics. He has a blog at HuffingtonPost.it and just published a memoir, Farnesina Radicale.

MARCO CAPPATO

Co-founder of Science for Democracy and Eumans and Treasurer of the "Luca Coscioni Association". Member of the European Parliament from 1999 to 2009, and EP Rapporteur on: "privacy in electronic communication"; "human rights in the world for 2007"; "production of opium for medical purposes in Afghanistan"; "public access to EU documents". Nominated for the "Politician of the year" award by "Wired" in 2003; winner of the "European of the Year" award organised by "the European voice".

FILOMENA GALLO

National Secretary of the "Luca Coscioni Association" since 2012. Lawyer before the Italian Court of Cassation, she is an expert in legislative issues concerning human biotechnology. For 10 years she has taught Law and Bioethics of Human Biotechnologies at the University of Teramo. Since 2005, she has promoted and followed most of the legal proceedings that led Italy's Constitutional Court to declare the unconstitutionality of the national Law 40/2004 on assisted reproductive techniques. She has collaborated with the Ministry of European Affairs and the Italian Drug Agency; a frequent commentator on bioethical issues in the national media. Founder of Amica Cicogna Onlus.

H.E. SARAH MBI ENOW ANYANG

H.E. Sarah Mbi Enow Anyang, from Cameroon, was elected as the new Commissioner for Human Resources, Science and Technology of the African Union Commission. H.E. Anyang has over fifteen (15) years' experience in the field of Academia.

EMANUELA DEL RE

Emanuela C. Del Re is Vice-Minister of Foreign Affairs and International Cooperation. Elected member of the Italian Parliament since 2018. Italian scholar, sociologist, she is an expert in foreign affairs issues, conflict studies, migrations, refugee and minorities issues and religious phenomena. She has carried out long researches on field in conflict areas and areas in transition since 1990 (Balkans, the Caucasus, North Africa, the Middle East and other). Tenured researcher, Associated Professor in Sociology, she has been Jean Monnet Professor (Univ. La Sapienza of Rome). She has been Researcher at the European University Institute (1997-2000) and Research Fellow at the University of Rome "La Sapienza" (2001-2003). Panelist and speaker in many

international fora. Member of numerous think tanks, institutes and organizations. Author of a vast number of scientific essays and volumes, and director of documentaries. She has been International Electoral Observer for the UN, EU, OSCE in more than 15 missions.

ANGELA MELO

Angela Melo entered UNESCO in March 2009 and is currently the Director of the Ethics, Youth and Sport Division of the Social and Human Sciences Sector. In the past Angela Melo held a number of different positions in the Mozambican Ministry of Justice, including as Criminal Prosecutor, representative of the Attorney General for criminal matters at the Supreme Court and Supervisor for National Juridical and Jurisdictional Service. She was also a Technical Member of the Technical Council of the Ministry of Justice, National Coordinator for drafting legislation and regulation about drugs and money laundering, Technical Member of the Mozambique Delegation for Negotiations on the Rome Statute of the International Criminal Court and its Rules of Procedures, headed Mozambique's delegation at the negotiations on the protocols of the Southern African Development Community (SADC) and was a Technical Member of the delegation of the Mozambique World Bank for negotiations on Judicial and Legal Reform. She was also Senior Legal Counsellor on public and private international law to Mozambique's Minister of Justice, with special responsibility for issues related to international human rights and criminal internal law. From 2001 to 2007, Angela Melo was Vice-President of the African Commission on Human and People's Rights (ACHPR) and Special Rapporteur to the ACHPR (African Union organ). She was the President of the ACHPR's Working Group on Economic, Social and Cultural Rights and for the Working Group on Specific Issues related to the Works of the ACHPR, including on the Review of its Rules of Procedure.

MIKEL MANCISIDOR

Lawyer and Doctor in International Relations and Diplomacy, is a UN Independent Expert Member of the Committee on Economic, Social and Cultural Rights (CESCR) since 2013. He was Director of UNESCO Center at the Basque Country (2004-2014) and teaches International Human Rights Law at the Deusto University, Washington College of Law at the American University and International Institute of Human Rights Rene Cassin. Ha was awarded the Golden Medal for Human Rights (2013) by the Liga Española de Derechos Humanos, and the Eusko Ikaskuntza (2020) Prize of Humanities, Culture, Arts and Social Sciences. He has worked on International Human Rights Law, International Organizations, International Relations, Civil Diplomacy, Culture of Peace, Cultural Rights and the Human Right to Water and Sanitation. Mikel Mancisidor was a Rapporteur for the General Comment on Science recently adopted by the CESCR.

RICHARD J. ROBERTS

Dr. Richard J. Roberts is the Chief Scientific Officer at New England Biolabs, Beverly, Massachusetts. He received a Ph.D. in Organic Chemistry in 1968 from Sheffield University and worked as a postdoctoral fellow at Harvard before moving to Cold Spring Harbor Laboratory. In 1977 his laboratory discovered split genes and mRNA splicing for which he received the Nobel Prize in Medicine in 1993. In that same year his laboratory, in collaboration with Xiaodong Cheng, discovered base flipping. He now focuses on bioinformatic analysis of genome sequences and studies of bacterial DNA methylation.

MICHELE DE LUCA

Michele De Luca, MD, is Director of the Centre for Regenerative Medicine "Stefano Ferrari" and of the Interdepartmental Centre for Stem Cells and Regenerative Medicine at the University of Modena and Reggio Emilia and Scientific Director and founder of the university spin-off Holostem. He has dedicated most of his scientific activities to translational medicine. He is recognised as leading scientist in human squamous epithelial stem cell biology aimed at the development of epithelial stem cell-mediated cell therapy and gene therapy.

MALIN PARMAR

Malin Parmar is a professor in cellular neuroscience at Lund University in Sweden and a New York Stem Cell Foundation – Robertson investigator. Her research has a strong translational focus. She leads the European effort STEM-PD, designed to bring stem cell-derived dopamine neurons to clinical trials, and she collaborates within European and International networks as well as Industry partners to develop new, cell based therapies for brain repair with focus on Parkinson's Disease.

PETE COFFEY

Professor Pete Coffey, DPhil, is Theme Lead of Development, Ageing and Disease at University College London's Institute of Ophthalmology and the Co-Executive Director of Translation at UC Santa Barbara's Center for Stem Cell Biology and Engineering. His achievements include the launch of the London Project to Cure Blindness that aims to develop a stem cell therapy for the majority of all types of age-related macular degeneration, seminal work (as described by Debrossy & Dunnett, Nature Neuroscience 2001) on retinal transplantation.

GHADA EL-KAMAH

Ghada El-Kamah MBBCh, MSc, PhD, Professor and Head of the Clinical Genetics department, National Research Centre (NRC) focuses on inherited disorders and genomics. She received her Clinical training at NRC, molecular training at NRC; Gaslini, Italy, tissue engineering (Neuss, Germany) and research ethics at NRC. Coordinator of the Hereditary Blood Disorders and Genodermatoses Clinics; Research Teams. Board member in the African Society of Human Genetics and Egyptian committee for pathology training-genetics. Ethical coordinator between the Clinical Genetics department and IRB-NRC.

PIA LOCATELLI

Pia Elda Locatelli (born 13 August 1949 in Villa d'Almè, Bergamo) is an Italian politician and Member of the European Parliament for North-West with the Italian Socialist Democrats, part of the Socialist Group and sits on the European Parliament's Committee on Industry, Research and Energy and its Committee on Women's Rights and Gender Equality. She is a substitute for the Committee on Employment and Social Affairs and a member of the Delegation for relations with Iran. From 2008 to 2010 she was the President of the Italian Socialist Party. In the 2013 Italian general election she was elected in the Chamber of Deputies with the Democratic Party, representing the PSI.

MICHELE USUELLI

Regional Councillor of Lombardia, +Europa con Emma Bonino; MD neonatologist; Partnership for Maternal Neonatal and Child Health: focal point for Italian Society of Neonatology. Michele is now a politician after a life dedicated to neonatal care. He has been managing maternal-neonatal projects in Afghanistan, Cambodia, Sudan, Malawi, Sierra Leone and CAR for 8 years. While engaged to the clinical management of the newborns and staff training on the job within the continuum of care, he has found out that friendly free of charge contraceptive services are welcomed to a vast part of women wherever and this helps reducing maternal and neonatal mortality; he translates it now in political decisions.

CONSOLATA OPIYO

Consolata is a leader representing young people living with HIV from East and Southern Africa on the board of the Global Network of Young People living with HIV. She also sits on the steering committee of the Adolescent Treatment Coalition, hosted by the International Aids Society. She is the Vice Chair of the International Community of Women Living with HIV East Africa. She is an activist, public and motivational speaker, facilitator and trainer of trainers. She is a passionate SRHR advocate who has not only amplified AGYW voices but also represented young women in both national, regional and international platforms.

MICHELE D'ALESSANDRO

Michele D'Alessandro works at the International Relations Office of Doctors with Africa CUAMM. After specializing in peace and conflict studies, he has worked as a human rights observer in Colombia, an intern at the Italian Embassy to Ethiopia, a trainee at the European Parliament in Belgium, and a consultant for the ILO in Lebanon. He earned his MA in European and International Studies from the University of Trento, and conducted 3 years of academic research in the Horn of Africa.

VITTORIA BRAMBILLA

Vittoria Brambilla obtained her PhD in Plant Biology at the University of Milan in 2007 and worked as a researcher at the Heinrich Heine University in Duesseldorf and at the Max Planck Institute for Plant Breeding Research in Cologne before moving back to Milan in 2011. She is currently Assistant Professor at the University of Milan, where she runs a research group dealing with rice developmental biology. She applies knowledge from basic research to rice breeding and she fights for using genome editing tools like CRISPR.

MARGARET KAREMBU

Dr. Margaret Karembu is Director of ISAAA's *Africa*Center based in Kenya. She oversees the Africa-based Biotechnology Information Centers that work with national programs to enhance science communication and enabling environment for modern biosciences. A seasoned science communication educator, Margaret has mentored science communication champions across Africa and provides opportunity to showcase these skills through the month *Drumbeat – Africa Bioscience Trends* and the Africa Biennial Biosciences Communication (ABBC) platform. She holds a PhD in Environmental Science Education from Kenyatta University, Kenya.

MARC HEIJDE

Marc Heijde was trained as a plant molecular biologist and bio-technologist. After a PhD at the Ecole Normale Supérieure (Paris, France), he pursued his scientific career in the academic world at the Universities of Freiburg (Germany) and Geneva (Switzerland) before moving to VIB (Flemish Institute for Biotechnology in Belgium) as a researcher. In 2015, with the strong conviction that science and innovation is central to the development of a sustainable agriculture and agribusiness he joined the VIB_International Plant Biotechnology Outreach (IPBO) founded by Prof. Marc Van Montagu (World Food Prize 2013). Marc is now the program manager of IPBO, he is also the coordinator of the EU-LEAP-agri project CLISMABAN aiming at the creation of climate smart banana varieties that will meet the expectations of the farmer and the consumers. He is also administrator of the Marc and Nora Van Montagu Fund. He has previously been project manager of the International Industrial Biotechnology Network funded by UNIDO. With a global network of stakeholders involved in Plant Biotechnology, breeding and related biosafety, Marc develops partnerships for research, innovation, and capacity building with the ambition to further encourage the set-up of a more sustainable and science based agriculture with a focus on Sub Saharan Africa.

EMMANUEL OKOGBENIN

Emmanuel Okogbenin is a Molecular Breeder with additional professional background in Agronomy and plant physiology. He has over 28 years working experience as cassava scientist in both national and international organizations in both Africa and Latin America. He is currently the Director for Program Development and Commercialization at the African Agricultural Technology Foundation, Kenya. His current duties include facilitating access and transfer of technologies through public private partnership for commercial and sustainable agriculture.

FARES MILI

Doctorate in Medicine: 1985; Specialty Degree in Pneumology: 1985; Master Degree of Tobacology: 2010; University degree of Addictology: 2013; Master Degree Tobacco Treatment Specialist (CTTS mayo Clinic Rochester Minnesota) February 2017; National Certificate in Tobacco Treatment Practice (NCTTP) by the Association for Addiction Professionals (NAADAC) and the Association for the Treatment of Tobacco Use and Dependence (ATTUD). December 2018; Chairman of The Tunisian Society of Tobacology and Addictive Behavior "STTACA") May 2017; Executive board member of the Tunisian Society of Respiratory Diseases and Allergology (STMRA) 2012-2017; Member of the French Speaking Pneumology Society (SPLF) since 2013; Member of the European Respiratory Society (ERS) since 2015; Member of the Tunisian National Committee for Tobacco Control; WHO consultant.

TEQUILA V. BESTER

Tequila has more than 15 years of professional experience working in civil society, addressing issues dealing with civil rights, disability and elderly rights, labor and employment advocacy, immigration, and mental health advocacy. She holds a Master of Science degree in Counseling Psychology from Alaska Pacific University and Juris Doctor from New England Law, Boston, with concentration in Public International Law. She is Programme Coordinator at FIHRRST, implementing the organization's second and third pillar: Human Rights Cities, Vulnerable Persons and Other Social Issues.

FEDERICO BINDA

Federico is Assistant Professor (Ricercatore) in pure mathematics at the University of Milan. He holds master degrees (University of Milan and University of Paris XI) and a PhD (University of Duisburg-Essen) in mathematics, and he has been a visiting scholar at the Hausdorff institute for mathematics (Bonn, Germany), the Tata Institute of Fundamental Research (Mumbai, India), the Institut Mittag-Leffler (Djursholm, Sweden), the Isaac Newton Institute (Cambridge, UK), and the University of Tokyo. Since September 2017, he is a board member of the Luca Coscioni Association for the freedom of scientific research. In Science for Democracy Federico works on Open Science and Open Access. He tweets as @fedebinda.

ROBERTO CASO

Co-director of Trento LawTech Group, is Associate Professor of Comparative Private Law at University of Trento, Faculty of Law, where he teaches Comparative Intellectual Property Law, Comparative Privacy Law, Copyright law and Art, CopyrightX Trento. He is author and editor of publications in the field of Intellectual Property, Privacy and Personal Data Protection. He is President of the Italian Association for the Promotion of Open Science [AISA]. Associate member of the Centre for Intellectual Property Policy (CIPP), McGill University (Montréal).

MUSHABE NORMAN

Mushabe Norman holds an MSc in Zoology of Makerere University and currently works as a Science Consultant for UNESCO Liaison Office to the African Union and the United Nations Economic Commission for Africa in Addis Ababa, Ethiopia. Previously, Norman has worked at the African Union Commission as a Project Officer for the capacity building project related to Multilateral Environmental Agreements (MEAs) in the Department of Rural Economy and Agriculture. He has over 9 years working experience in providing policy, institutional and technical support to governments, national and international organizations on science based programmes, including biodiversity conservation, fisheries/aquaculture development, environment and natural resources management. He is also an alumnus of the Prestigious Young African Leaders Initiative (YALI).

MARGARETH GFRERER

Margareth Gfrerer holds a PhD in Economics and a MA in Economics Education from University Graz (Austria) and a MA in International Commerce from Vienna University of Economics. After years in industry she returned to University as senior lecturer and researcher - first to FH-JOANNUM (Austria); followed by different university assignments in Indonesia. She has been involved in numerous international projects in the field of infrastructure management prior her current assignment in Ethiopia, where her focus is on Open Science and its impacts.

SOLOMON MEKONNEN

Dr. Solomon Mekonnen is an Academic Staff in the Library with the rank of Assistant Professor and Open Access Coordinator at the Addis Ababa University (AAU). Apart from his role at AAU, Solomon coordinates nationally Open Access Programme of an international network called Electronic Information for Libraries (EIFL) representing Consortium of Ethiopian Academic and Research Libraries. He is also a local organizer in Ethiopia for an international network called Open Knowledge Foundation. As part of his role as local organizer,

he coordinates the Open Knowledge community in Ethiopia focusing on open data and open science. Solomon has participated in many projects related to open data and open access at the national and institutional level including a project on opening and visualizing Ethiopian election 2015 data, Ethiopian Journals Online, National Digital Repository and national open access policy. He also organized and run various workshops and trainings on open access and open data. Solomon completed his PhD in Information system from the University of South Africa.

FINAL RECOMMENDATIONS

6TH MEETING OF THE WORLD CONGRESS FOR FREEDOM OF SCIENTIFIC RESEARCH 25-26 FEBRUARY 2020, ADDIS ABABA, ETHIOPIA

1. Participants in the **Sixth meeting of the World Congress for Freedom of Scientific Research**, held in Addis Ababa, Ethiopia on 25-26 February 2020 at the African Union headquarters, entitled *"The right to enjoy the benefits of science, an African perspective"* wish to thank the Commission of the African Union in the person of Professor Sarah Mbi Enow Anyang Agbor, Commissioner for Science and Technology, and **Science for Democracy** for having promoted the event and the **Luca Coscioni Association** for organizing it.

2. The quality of the discussion and exchanges that it has generated, and the intellectual interaction of people with different expertise and backgrounds has enriched the Africa-focused debate on the therapeutic potential of stem cells, the importance of precision and genetic medicine, sexual and reproductive health and rights, new breeding techniques and the introduction of safer products on the market, as well as a more open access to science and data sustained by the promotion of civilian uses of artificial intelligence. The proceedings of the Congress, together with this outcome document, will now need to be shared in different constituencies all over the world as they address some of the most pressing issues mankind is facing.

3. What the meetings of the World Congress have identified over the years has proved to be central in the international agenda on issues relating to human progress, sustainable development and in particular on the protection and promotion of the "right to science" with all its implications, as contained in Article 15 of the International Covenant on Economic Social and Cultural Rights:

1. The States Parties to the present Covenant recognize 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.

Thereby reinforcing international Rule of Law.

4. Participants salute the General Comment on Science prepared by the United Nations Committee on Economic, Social and Cultural Rights, fully endorsing the document where it states that:

"This set of rights, entitlements, liberties, duties or obligations related to science, might be brought together in a single broad concept named "the human right to science" in the same way that, for example, "the human right to health" encompasses a broad set of rights and freedoms affecting human wealth and well-being. This approach and this name have already been adopted by the Special Rapporteur on Cultural Rights, by UNESCO, by some international conferences and summits and by some important scientific organizations and publications.

5. Participants call on the UN to develop guidelines on the basis of the General Comment to assist Member States in sharing their efforts towards the implementation of the many aspects of the "right to science", believing that its full enjoyment can structurally contribute to the achievement of the Sustainable Development Goals and become a pillar for the future consolidation of the Agenda 2063, that aims to deliver on Africa's goals for inclusive and sustainable development, unity, self-determination, freedom, progress and prosperity.

6. Science literacy and communication should be promoted and improved to ensure that all individuals have access to reliable and up-to-date information. Participants believe that freedom of research, the sharing of knowledge and the right to enjoy the benefits of science for all should be systematically taken into consideration during decision-making processes.

7. The panel discussions of the Congress have highlighted the need to direct substantial investments into human capital, health, education, and agricultural services, as well as in improving the situation of women as important resources for the welfare, wellbeing and sustainable development of societies. Participants believe that existing science evaluation systems and reward structures are obstacles to a broad implementation of Open Science, and call for change following UNESCO's recommendations. To this end, Participants appeal to the United Nations so that a Special Rapporteur on the "right to science" is established to better monitor the implementation of the multiple aspects of the right contained in the General Comment.

8. The "right to enjoy the benefits of science", in particular, alongside discussions on the precautionary principle, should guide a comprehensive, holistic and evidence-based approach to decisions on the latest developments of scientific research and its applications with the hope of

engaging as many States and stakeholders as possible, in a regulatory process that can only be trans-national.

9. Participants believe that Gender Equality in Science, Technology and Innovation (STI) is crucial and urgent. To this end, Participants call for monitoring progress in terms of gender equality and equal participation in STI fields. Actions to support efforts in the promotion of gender diversity in STI should be prioritized in all countries.

10. Participants invite Members States of the African Union to initiate all the necessary procedural steps to ratify the Optional Protocol of the International Covenant on Economic Social and Cultural Rights, adopted by the UN General Assembly on 10 December 2008, which entered into force on 5 May 2013. The protocol establishes an individual complaints mechanism for the Covenant that can assist States to address the need to update legislations concerning economic, social and cultural issues, including all aspects pertaining to science.

11. Concerning multilateral relations, Participants believe that the notion of "Third Country" – such as the one foreseen in the upcoming Horizon Europe, the 9th Research and Innovation framework program of the European Union – should be updated with particular attention to the issues discussed during the 6th World Congress in order to foster the "Right to Science".

Participants therefore call on the European Union to take into consideration the peculiarities and complexity presented by the African continent when evaluating the Third Country Openness Criteria for the participation to the Union programmes. Particular attention should be given to the beneficial effects that such a participation would have on the social well-being of citizens, while guaranteeing fair and transparent policies on intellectual property rights.

12. Participants commit to pursue the goals set in these recommendations of the 6th World Congress and remain available to cooperate among themselves to pursue the implementation of these recommendations.

13. Participants hope that the next meeting of the World Congress will be organized in a region of the world where particular efforts remain necessary to promote and protect the "right to science" for the promotion of individual and societal welfare and invite the promoters and organizers to look again at Africa as a possible venue.

HOSTING ORGANISATIONS

SCIENCE FOR DEMOCRACY

Science for Democracy is a platform launched in October 2018, by some members of Associazione Luca Coscioni to promote the affirmation of the "right to science" through a dialogue between the scientific community and decision-makers all over the world at different levels. In this context, since its inception Science for Democracy has followed the drafting process of a "General Comment on Science" by the UN Committee on Economic, Social and Cultural Rights, which is further clarifying the numerous implications deriving from the implementation of Article 15 of the ICESCR. Science for Democracy has organized ad hoc panel discussions and side-events at the UN in Geneva and Vienna to raise some of the issues that could have benefited from specific mentions in the General Comment, such as human and vegetal biotechnologies, reproductive health, controlled narcotics for therapeutic purposes, gender equality in science, as well as open access to scientific literature. To complement more in-depth discussions, Science for Democracy has also organized public demonstrations to raise awareness for the general public. The "**Give crispr a chance**" snack organized in front of the European Parliament in March 2019, and repeated at the Polytechnic University in Bari, Italy, are two such examples. In front of a large crowd, mostly made up of students, speeches were delivered explaining what crispr is and the repercussions of the **25 July 2018 ruling** of the European Court of Justice. A crispr-produced rice meal was consumed by scientists to demonstrate the safety of the technique. The themes covered by Science for Democracy are wide-ranging, and in general every scientific issue is relevant. In order to engage decision-makers, a document presenting **11 points was submitted to candidates** in the European Parliament elections in spring 2019. The text includes issues ranging from sexual and reproductive health rights, disability, end of life decisions, human and vegetal genome editing, to embryo research, controlled narcotics and policy evaluation processes and impact evaluation.
Official Website: **www.sciencefordemocracy.org**

ASSOCIAZIONE LUCA COSCIONI

Associazione Luca Coscioni is dedicated to the promotion of scientific research and the ascertainment of civil liberties in accordance with regional and international instruments of human rights.
The Association carries out its activities through raising public awareness, promoting advocacy campaigns, providing legal assistance to people whose rights are violated, launching action alerts for decision-makers, and generating attention to specific themes, also through civil disobedience and court cases.
The fields of action of the Associazione Luca Coscioni are wide-ranging, from the freedom of scientific research and disability rights to reproductive rights (assisted reproduction and

contraception), end of life decisions and drug policy. Other campaigns include appeals for more funding for research and the debureaucratization of health systems.
Official Website: **Associazione Luca Coscioni**

AFRICAN UNION

The African Union is a continental union of 55 member states for a total of over 1 billion people. Its aims include the promotion of further continental unity, socio-economic integration, the coordination of positions at the international level, and an improvement of living standards. Some of the goals of the African Union correspond to the themes of the World Congress for Freedom of Scientific Research, namely the promotion of scientific research, the participation of women in society and decision-making and an improvement of public health. The Assembly of the African Union is a gathering of the heads of state and of government, who meet twice a year and take the main decisions. The secretariat of the African Union, the Commission, carries out its daily operations and is based in Addis Ababa.
Official Website: **African Union**

TAKE ACTION

Science for Democracy is an international platform of scientists and academics that promote the affirmation of the "right to science" through a dialogue between the scientific community and decision-makers all over the world at different levels.
There are a lot of ways to get involved with Science for Democracy. You can join as a scientist-volunteer one of our projects, suggest a new area of action or simply support our actions with a contribution.

SUPPORT SCIENCE FOR DEMOCRACY

Science for Democracy's activities span from the promotion of the right to science at the United Nations to the organisation of the World Congress of Freedom of Scientific Research, to direct actions such as the engagement in European Citizens Initiative for the respect of the rule of law, carbon pricing and genome editing. We are constantly committed to increase the awareness on the biggest challenges of our time and design evidence-based solutions, through the organisation and participation of conferences, symposia, events.
Your contribution can help us increase the reach and the potential of all our initiatives.

LEARN MORE ABOUT WHAT YOU CAN DO

www.sciencefordemocracy.org/take-action/
info@sciencefordemocracy.org

6TH MEETING
ADDIS ABABA 25-26|02|2020

WORLD CONGRESS FOR FREEDOM OF SCIENTIFIC RESEARCH

Promoted by African Union SCIENCE FOR DEMOCRACY Organized by ALC ASSOCIAZIONE LUCA COSCIONI PER LA LIBERTÀ DI RICERCA SCIENTIFICA

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