

Association's Members:

**Maria Antonietta FARINA  
COSCIONI; Gilberto  
CORBELLINI, Piergiorgio  
STRATA, Piergiorgio  
WELBY**

Presidents  
**Josè SARAMAGO**  
Honor president  
**Marco CAPPATO**  
Segretary  
**Maurizio TURCO**  
Treasurer  
**Giulia SIMI**  
**Rocco BERARDO**  
Vice-secretaries

**Board:** Rita Bernardini, Gaia Carretta, Andrea Francioni, Diego Galli, Filomena Gallo, Mirella Parachini, Marco Perduca, Donatella Poretti, Maurizio Provenza

**General Council:** Adolfo Allegra, Angiolo Bandinelli, Mauro Barni, Maurizio Bolognetti, Davide Cervellin, Paola Cirio, Tonina Cordedda, Giulio Cossu, Marcello Crivellini, Gianandrea Dagnino, Domenico Danza, Patrizia De Fusco, Sabrina Di Giulio, Marco Favara, Valerio Federico, Anna Pia Ferraretti, Francesco Fiorentino, Carlo Flamigni, Antonino Forabosco, Alessandro Frezzato, Cesare Galli, Luca Gianaroli, Claudio Giorlandino, Marisa Jaconi, Chiara Lalli, Fabio Marazzi, Filippo Meucci, Severino Mingroni, Luigi Montevicchi, Claudia Moretti, Demetrio Neri, Francesco Orzi, Maria Pamini, Barbara Sanua, Gianfranco Spadaccia, Bruno Tescari, Antonio Tessitore, Silvio Viale

**Luca Coscioni has gathered support from 95 Nobel Prizes:**

Alexei Abrikosov, Peter Agre, George Akerlof, Zhores Alferov, Sidney Altman, Philip Anderson, Werner Arber, Kenneth J. Arrow, David Baltimore, Baruj Benacerraf, Paul Berg, Gunter Blobel, Norman E. Borlaug, Paul Boyer, Thomas Cech, Stanley Cohen, Leon N. Cooper, Robert Curl, Pierre Degennes, Johann Deisenhofer, Cristian De Duve, John B. Fenn, Edmond H. Fischer, Val Fitch, Jerome I. Friedman, Ivar Giaever, Walter Gilbert, Vitaly Ginsburg, Donald A. Glaser, Shelly Glashow, Clive W. J. Granger, Paul Greengard, Roger Guillemin, Lee Hartwell, Herbert A. Hauptman, James J. Heckman, Alan Heeger, Dudley Herschbach, Gerard T Hooft, H. Robert Horvitz, R. Timothy Hunt, Arthur Kornberg, Herbert Kroemer, Paul C. Lauterbur, Leon M. Lederman, Jean-Marie Lehn, Alan G. Macdiarmid, Rudolph Marcus, Daniel Mcfadden, Robert Merton, Mario Molina, Kary B. Mullis, Erwin Neher, Christiane Nuesslein-Volhard, Paul M. Nurse, George A. Olah, Douglas D. Osheroff, Martin L. Perl, John Polanyi, Richard J. Roberts, Josè Saramago, Jens Chr. Skou, Richard E. Smalley, Jack Steinberger, Horst L. Stormer, John Sulston, Richard E. Taylor, Donnal E. Thomas, Daniel C. Tsui, Harold Varmus, Martinus Veltman, Klaus Von Klitzing, John Walker, Steven Weinberg, Carl Wieman, Kurt Wuthrich, Rolf Zinkernagel, Sir James Black, Herbert C. Brown, Steven Chu, Claude Cohen-Tannoudji, Richard R. Ernst, Robert Furchgott, Antony Hewish, Sir Godfrey Hounsfield, Sir Aaron Klug, Walter Kohn, Sir Harold W. Kroto, William D. Phillips, Ilya Prigogine, Reinhard Selten, Hamilton O. Smith, Robert M. Solow, Henri Taube, Sir John Vane.



**Roma (Italia)**  
Via di Torre Argentina 76 00186  
tel.: +39.06.68979378  
fax: +39.06.68805396  
**New York (Usa)**  
866 U.N. Plaza, # 408 - 10017 New York, NY  
tel.: +1.212.9801031  
fax: +1.212.9801072  
[www.lucacoscioni.org](http://www.lucacoscioni.org)  
email: [info@associazioneoscioni.org](mailto:info@associazioneoscioni.org)

To the Kind Attn. of the  
**EUROPEAN COMMISSION**  
[einclusion@ec.europa.eu](mailto:einclusion@ec.europa.eu)

Rome, August 15, 2007

**Subject:** Public Consultation on the European e-Inclusion Strategy - Position Paper

**(On-line public consultation - casenumber: 679659454041322607)**

The LUCA COSCIONI ASSOCIATION is pleased to submit a Position Paper with reference to the Public Consultation on the European e-Inclusion Strategy aimed at gathering opinions from the wider public on e-Inclusion (digital inclusion) in addition to the on line form, on the main areas of interest listed below:

- e-Accessibility.
- Inclusive e-Government.
- Information & communication technologies for active ageing at work.
- The role of stakeholders in reaching e-Inclusion goals

For over six years, the LUCA COSCIONI ASSOCIATION has been engaged in Italy and at the international level to pursue several goals, the Association believes that some of the objectives reached at the national level could provide fruitful suggestions to the European strategy.

On 18 May 2007, the LUCA COSCIONI ASSOCIATION has already participated in an interactive dialogue with the European Commission submitting its opinion within the framework of the European Commission Public Consultation "Identification of services of social value in Europe that could benefit from single European freephone numbers starting with 116", concerning the Decision adopted by the European Commission and requiring Member States to reserve the six-digit number range starting with the digits 116 for services of social value in Europe. On that occasion, the LUCA COSCIONI ASSOCIATION suggested to dedicate some of the '116' numbers to provide information and assistance to people with disabilities, those services should, along the lines of examples already in place in different EU Member States, include some free directory enquiry services not currently provided all over the European Union, in particular relay services for text telephony and relay services for video telephony. The suggestions presented by the LUCA COSCIONI ASSOCIATION were acknowledged by the Commission, which on 11 July last asked to receive more detailed info on the services suggested for widespread adoption. The LUCA COSCIONI ASSOCIATION is working on a document that will be submitted by mid-October.

The LUCA COSCIONI ASSOCIATION suggestions were derived from a national campaign to promote the adoption of free-of-charge text messages (SMS) for deaf people, which were at the centre of an international congress organized by the Association in Milan last January entitled "Technologies and reforms against disabilities", which saw the participation of representatives of the European Commission.

**As stated in the Milan final document, the LUCA COSCIONI ASSOCIATION believes in a comprehensive revision of EU regulatory framework for electronic communication networks and services, in particular of the Directive 2002/22/EC of the European**

LUCA COSCIONI ASSOCIATION FOR FREEDOM OF SCIENTIFIC RESEARCH

Parliament and of the Council of 7 March 2002 on universal service and users' rights relating to electronic communications networks and services (Universal Service Directive), so that the universal service for the disabled people include:

1. broadband territorial coverage;
2. SMS and video calls at a cost price (partial exemption) for deaf people and people with serious disabilities according to Italian law 104/92, art. 3, par. 3;
3. periodic (every six months) invoicing of the above-mentioned services, with clarifications of benefits, mainly partial exemption, for people with serious disabilities;
4. subtitling of television programs, starting from public service messages, news and political information programs;
5. implementation of the digital signature.

The suggestions were in part derived from pieces of Italian legislations that adopted years ago have not yet been implemented.

Hence the LUCA COSCIONI ASSOCIATION believes that while working for the harmonisation of the regulations in this field it is crucial to work towards the prompt implementation of the various European directives and national laws already in force in all EU Member States to ensure the public funding of the proposed actions and to allow the provision of public services free of charge.

Lastly, the LUCA COSCIONI ASSOCIATION believes that particular attention should be given to the provision contained in the UN Convention on the Rights of People with Disabilities - mainly including its provisions on accessibility (art. 9) - and to the acceleration of its implementation in all EU Member States with a view of engaging the Union in international programs to assist poor and or developing countries to follow suit.

In addition to the above the LUCA COSCIONI ASSOCIATION asks to be involved in the drafting of the Green paper by the European Commission on the universal service directive with particular reference to people with disabilities and elderly people.

### The Luca Coscioni Association

The Associazione Luca Coscioni per la libertà di ricerca scientifica (Luca Coscioni Association for Freedom of Scientific Research, LUCA COSCIONI ASSOCIATION), was founded in 2002, is constituent member of the international non-governmental organization Nonviolent Radical Party, in consultative status with the UN Economic and Social Council.

The LUCA COSCIONI ASSOCIATION is named after Dr. Luca Coscioni, a Professor of Environmental Economics at the University of Viterbo (Italy), who passed away on 20 February 2006, after having suffered for ten years from Amyotrophic Lateral Sclerosis (ALS).

In the early 1990s, Dr. Coscioni started to get involved in local politics in his native Viterbo as member of the city council; in 1996, while training for the New York Marathon, he was diagnosed with ALS, which, in five years, confined him to a wheelchair.

In 2000, Dr. Coscioni decided to bring his health situation to the general public as a political case in Italy denouncing the lack of appropriate regulation and public funding to allow scientific research, in particular the one on embryonic stem cells. In order to do that, in that same year, he was elected member of the General Council of a political organization affiliated with Italy's Radical Party.

At the 2001 Italian parliamentary elections, Dr. Coscioni ran for the Chamber of Deputies in the same list of former European Commissioner Emma Bonino (Radical Party member). On that occasion the Nobel Laureate for Literature José Saramago sent him a message adding his support to the one expressed by scores of scientists and Nobel Laureates stating that "perhaps the support of a mere writer like me will seem a little or a lot out of place in a list of scientific leaders who, with their names and their prestige, seal the words spoken by Luca Coscioni. In any case, my name is at your disposal, so that the light of reason and human respect can illuminate the gloomy spirits of those who believe themselves to be, still and always, the masters of their destinies. For a long time we waited for the day to break, we were exhausted by the

waiting, until all of a sudden the courage of a man, rendered silent by a terrible disease, gave us renewed strength".

Though Dr. Coscioni was not elected to Parliament, he received the support of hundreds of scientists, physicians, patients as well as politicians and intellectuals. Later in that year, a similar show of support accompanied his unsuccessful bid to become a member of the National Bioethics Committee.

In 2002, together with Emma Bonino and Radical Party's founder Marco Pannella, Dr. Coscioni founded his association in order to promote freedom of scientific research, with particular attention to research on embryonic stem cells, a technique that was running the risk of being severely hindered by a draft bill before the Italian Senate.

The main objectives of the LUCA COSCIONI ASSOCIATION are:

- the promotion of freedom of scientific research and cure;
- the promotion of projects and technologies for "Independent Living";
- the ascertainment of civil and political rights of patients and people with disabilities.

After the adoption on February 2004, of the bill that prohibited embryonic stem cells research, and strictly limited *in vitro* fertilization in Italy, the LUCA COSCIONI ASSOCIATION and the Italian Radicals launched a referendum campaign to repeal it. The referendum was voted upon in June 2005, despite an overwhelming majority of those that voted supported the proposal to radically amend the law, the referendum did not reach the quorum of 50% necessary for the vote to be valid.

Over the Summer 2004, the LUCA COSCIONI ASSOCIATION, together with the UN-affiliated NGO, the Transnational Radical Party (TRP), launched a campaign to discourage the adoption of an international convention to ban all forms of cloning. Four months of international mobilization coordinated with the US based Coalition for the Advancement of Medical Research and the Genetics Policy Institute were able to substantially diminish the proposal, which was transformed in a declaration and endorsed by some 80 UN members in February 2005.

To better coordinate, and institutionalize, her international activities, in October 2004 the LUCA COSCIONI ASSOCIATION promoted the creation of an international network to promote freedom of scientific research. A first meeting was organized in Rome to launch a World Congress, which was convened in Rome at the city's Capital Hill from 16 to 18 February 2006 at the presence of scientists, researchers, politicians and advocates coming from all over Europe and the United States. The meeting was opened by Dr. Coscioni with a video message, his last public appearance - he passed away on 20 February 2006 on the eve of the filing of candidates for the Italian Parliament where he was supposed to head the list of the newly founded party of the "Rose in the Fist", an alliance of Liberals, Socialists and Radicals.

Throughout 2006, the LUCA COSCIONI ASSOCIATION has been involved in a campaign to promote the legalization of euthanasia; the main actor and testimonial, of this new struggle was Mr. Welby, a long-time member of the LUCA COSCIONI ASSOCIATION, affected by ALS since the 1980s, who after 90 days of struggle saw fulfilled his desire to end his life peacefully after a Dr. Mario Riccio sedated him and terminated the life support that Mr. Welby considered a torture rather than a treatment. The case stirred a national public debate on a variety of subjects, from euthanasia to the living will to the right not to be cured when the treatment is imposed against the patient's expressed will. Several bills were introduced before the Italian Senate to find ways to regulate several of the issues raised by Mr. Welby's case, among them one on the right-to-die.

In the last days of his struggle, Mr. Welby's ordeal became of international interest triggering interest and solidarity all over the world. His correspondence with the President of the Italian Republic was fully covered by several international media outlets.

While the promotion of scientific research and euthanasia remain the main issues of the LUCA COSCIONI ASSOCIATION work, over the years several *ad hoc* initiatives have also been promoted. The most significant, among others, is the campaign the LUCA COSCIONI ASSOCIATION launched in March 2006 to ask the Italian Authority for Communications to issue a regulation framework aimed at adopting text messages and video calls at a cost price for deaf people, since in Italy telecommunications companies charge 1,000% on the cost of text messages even of deaf people, who can send up to 20 SMSs a day. In the framework of this campaign, on 26 and 27 January last the LUCA COSCIONI ASSOCIATION held in Milan an International

Congress entitled "TECHNOLOGIES AND REFORMS AGAINST DISABILITIES - Digital and political revolution for "freedom of speech" and independent living". The congress was crucial in urging the Italian Minister for Health, who took part in the Congress, to decide a 10 M Euro funding for the acquisition of communication devices for people affected by amyotrophic lateral sclerosis.

On February 20, 2007, on the occasion of the first anniversary of Dr. Coscioni's death, a series of events were organized to commemorate his work and struggle to promote freedom of scientific research.

Since 2004 the Luca Coscioni Association acts as the Secretariat of the World Congress for Freedom of Scientific Research. In 2008 a second meeting of the World Congress will be organized in Istanbul, Turkey.

Over the years, Dr. Coscioni and the Association have received the support of 96 Nobel Laureates, the list is available at [www.lucacoscioni.it](http://www.lucacoscioni.it) and [www.freedomofresearch.org](http://www.freedomofresearch.org)