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A PROPOSAL FOR JOINT POPULAR S ON END OF LIFE TREATMENTS REFORMS IN THE EUROPEAN UNION

FIRST STEP: TIME FOR THE EUROPEAN LIVING WILL

❖ EXECUTIVE SUMMARY

Founded in 2002, Associazione Luca Coscioni¹ is an Italian based no-profit organisation aimed to promote civil liberties and human rights, in particular science, self-managed personal assistance, assisted reproductive technology, removal of architectural barriers, end-of-life choices, legalisation of euthanasia, access to medical cannabinoids and worldwide monitoring of laws and policies on science and self-determination. On a European and global scale Associazione Luca Coscioni operates with its partner organisations, Science for Democracy and the pan-European movement of popular initiative EUMANS.

Since 2006², Associazione Luca Coscioni has been at the forefront for **the right to choice concerning end of life decisions** in Italy. Through strategic litigation, citizens' initiatives and the civil disobedience of Marco Cappato³ (Treasurer of Associazione Luca Coscioni and President of EUMANS) and Mina Welby (Co-President of Associazione Luca Coscioni), we are committed to ensure citizens to "*be free until the end*".

In 2021, Associazione Luca Coscioni led the campaign for the collection of signatures aimed to **call for a referendum to legalise euthanasia in Italy** and engaged EU institutions to boost the debate and raise awareness at EU level.

Boosted by evidence of the failure of national approaches in providing a comprehensive response to health issues during Covid pandemic and consequently by the need to build a strong European Health Union, Associazione Luca Coscioni believes it's time to start a new phase of reforms where EU citizens' **end of life decisions are at the core of EU debate**.

Today, we call on experts, academia, NGOs, associations, MEPs, political parties, and EU citizens to engage in a fruitful debate aimed to create the conditions for guaranteeing dignity for all EU citizens.

¹ <https://associazionelucacoscioni.it>

² https://en.wikipedia.org/wiki/Piergiorgio_Welby

³ <https://www.associazionelucacoscioni.it/the-cappato-trial-step-by-step>

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For info: johagterberg@gmail.com (Representative of Associazione Luca Coscioni in the international networks), Carla Pisi c.pisi@sciencefordemocracy.org (Policy Advisor at Science for Democracy and EUMANS and activist of the Referendum Eutanasia Legale), Virginia Fiume virginia.fiume@eumans.eu (Coordinator of EUMANS)

To achieve this goal, we believe that a first step may be represented by **the introduction of a European Living Will Pass**, an instrument that would facilitate the legal recognition and binding nature of the living will in the EU (see paragraph below “A European Living Will Pass” for more details).

In this regard, we invite you to join our initiatives as well as to take part to our partner organisation EUMANS’ Congress **“Citizens Congress For Democracy and Sustainability”** scheduled to be held in Warsaw in March 2022. Associazione Luca Coscioni will participate in the Congress curating the session related to “End of Life Treatments”. It will be a precious occasion to cooperate to define common goals and strategies for the activation of participatory democracy instruments enabling a response at EU level on end of life choices.

❖ THE CAMPAIGN FOR A REFERENDUM FOR THE LEGALISATION OF EUTHANASIA IN ITALY (AND THE CONTRIBUTION OF ITALIANS ABROAD).

In April 2021, Associazione Luca Coscioni launched a campaign for the collection of 500.000 certified signatures aimed to call for a referendum **to partially abrogate art. 579 of criminal code (“Murder of the consenting party”)** which punishes anyone who causes the death of a man, with his consent, with imprisonment from six to fifteen years.

Thanks to the outstanding participation of civil society, **1.239.423 certified signatures** were collected in the short period of 1 July - 30 September 2021.

Howbeit, the astounding result did not stop us from keeping the debate alive.

Several advocacy initiatives are currently ongoing whilst the **Constitutional Court is evaluating the referendum question’s admissibility** that, hopefully, would allow citizens to vote between 15 April and 15 June 2022.

Why do we need the referendum?

1) Institutions are silent.

- In 1984, 37 years ago, Loris Fortuna, Socialist Party parliamentarian, prepared the first draft of a law on end of life, which has never been discussed as well as other drafts submitted afterwards.
- In 2013, a bill of popular initiative for the legalization of euthanasia (67 thousand signatures) was deposited at the Italian Chamber of Deputies. The Italian Parliament has been silent for years and has never tabled a discussion⁴.
- In 2018, the Constitutional Court acknowledged the lack of adequate protection for certain situations by the Italian end-of-life regulatory framework and gave the Parliament one year to intervene with appropriate discipline. Nevertheless, the

⁴ <https://www.eutanasialeale.it/proposta/>

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Parliament has never intervened. Its silence⁵ brought the Constitutional Court to declare the partial unconstitutionality of Article 580 of the Criminal Code in the ruling 249\2019 Cappato\DJ Fabo.

2) Possible Discriminations.

In Italian current legislation,

> **active euthanasia** is prohibited by both in the **direct version** (art. 579 cp murder of the consenting party) and in the **indirect version** (art. 580 c.p. incitement and suicide aid), without prejudice to the discriminatory requirements introduced by the Constitutional Court ruling 242\2019 (Cappato\DJ Fabo)

> **passive euthanasia** is considered criminally licit especially when the interruption of treatment has the aim of avoiding the c.d. "therapeutic obstinacy" and has been positivized by law 219/2017 (on the living will).

Possible discriminations arise because:

- > There are ambiguous cases that often do not allow easy to distinguish whether it is euthanasia by action or omission.
- > There are cases in which the simple interruption of treatments may not lead serious and suffering patients to death.
- > The Constitutional Court Ruling 242/2019 (Cappato/DJ Fabo) allows the person to procure assisted death only autonomously, but there are cases in which this person cannot physically take the drug, due to totally incapacitating illness.

❖ SEEDS FOR AN EU LEVEL END OF LIFE CAMPAIGN

- What we did

On 22 July 2021⁶, together with some MEPs from Renew Europe political group, Associazione Luca Coscioni has addressed a **letter to the President of the European Commission Ursula Von Der Leyen and to the Commissioner for Health and Food Safety Stella Kyriakides** aimed to raise attention over the state of play of end-of-life treatments across the European Union and to call for your action to guarantee dignity and the right to self-determination for all European citizens.

Namely, we focused on **5 issues**:

- 1) The need to collect more qualitative data in order to inform and influence policy-makers
- 2) EU funding to cover all Europeans' voices and choices
- 3) Enhancing dialogue with civil society
- 4) The cross-border portability of the living will
- 5) The free circulation of patients within the EU for end of life treatments

⁵ https://www.cortecostituzionale.it/documenti/comunicatistampa/CC_CS_20181024184707.pdf

⁶

<https://eumans.eu/end-life-treatments-letter-european-commission-signed-sophie-intveld-and-marco-cappato>

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The content of the letter has been translated into a proposal for the Conference on the Future of Europe⁷.

On 11 October 2021, the European Commission replied as follows:

- 1) **Regarding data availability**, the Commission is working on a European Health Data Space (EHDS), making it one of the building blocks of a stronger Health Union, for a trustworthy health data ecosystem. This will enable better measurement of health outcomes, empower citizens and create capabilities for the reuse of data for research and development and will enable over time the exchange of data across the full continuum of care from the development of medicines and treatments through the full patient journey.
- 2) **Regarding the EU funding**, the Commission invested over EUR 129.9 million to support research and innovation in the area of palliative care, end-of-life care, and empowerment of cancer patients and survivors under the former framework programme for research and innovation, Horizon 2020. This support is expected to be continued under the new programme, Horizon Europe. Moreover, end-of-life care is also an issue that will be addressed in the context of Europe's Beating Cancer Plan and the Mission on Cancer under the Horizon Europe Framework Programme for Research and Innovation (2021-2027).
- 3) **Regarding dialogue with civil society on health matters**, the Commission has launched the EU Health Policy Platform. At the request of its users, the Health Policy Platform can open networks to facilitate dialogue on any topic supported by the health community.
- 4) **Regarding cross-border application of patients' rights**, the Commission mentioned the Directive on the application of patients' rights in cross-border healthcare that gives EU citizens the right to seek healthcare in another Member State and to be (partially) reimbursed for the costs in accordance with the conditions of their health insurance. The definition of the healthcare benefits, including end-of-life treatment, is a matter for the national competent body. The content of the 'baskets of benefits' varies widely between countries.

On 12 October 2021, Associazione Luca Coscioni participated in the webinar organised by MEP Sophie in 't Veld **"EU Citizens' right to access to end of life treatments"**.

- **What the European Parliament is doing:**

Upon the initiative of MEP Sophie in 't Veld, the Renew Europe political group within the Civil Liberties, Justice and Home Affairs Committee of the EP asked for a study on the **"Right to Die in Dignity across Europe"**. The proposal was adopted and the study will probably be published in 2022.

- **What is our proposal**

1.a) An European Living Will Pass:

Our proposal is aimed to facilitate the legal recognition and binding nature of the living will in the EU, no matter in which Member State it has been written. Namely, **we advocate for the introduction of a European Living Will Pass**.

⁷ <https://futureu.europa.eu/processes/Health/f/3/proposals/91807>

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We believe that the freedom of movement of EU citizens (art. 45 TFEU) may imply the possibility for all citizens to exercise their rights wherever they are in the EU. **The portability of civil rights**, including those related to self-determination, is, indeed, to be protected and respected as a human right.

Learning from Covid pandemic which has accelerated the digital transformation, our initial proposal is the development of QR code technology enabling the reading of the living will's content from any device. This would facilitate the **prompt exchange of information regarding end of life provisions among Member States** which have already introduced the living will in their legislations.

In this regard, it's important to bear in mind that not all Member States have introduced **rules for advance directives in their legislations** (at the moment, only 15 MSs have developed specific rules on advance directives⁸ which, however, seem to be heterogeneous)⁹ Therefore our proposal only regards the exchange of information among MSs where advance directives are possible.

We envisage that a citizen can express his/her advance directives and provide his/her consent in accordance with General Data Protection Regulation 2016/679 to have it published in a national/European database. **Each living will will be then associated with a QR code.** By doing so, should the EU citizen be unable to make or communicate his/her own decisions regarding e.g. whether or not refusing medical treatments in a different MSs to the one where he/she express his/her will, the doctor can easily verify the existence of a living will and promptly act accordingly.

Taking into consideration the differences in the content of different living wills, doctors would be only bound by the provisions of the living will which are also binding in their MSs.

The mutual recognition of living wills and the interconnections of national registers would bring certain advantages in the context of the European Health Union by avoiding bureaucracy delays due to administrative or judicial procedures and litigation.

The exchange of information provided with the proposed European Living Will Pass would be only an initial step in an auspicious broader perspective which would bring, in a long term, to the development of interoperability protocols and harmonization of National and European Databases of Living Wills in the framework of a European Health Union.

1.b) Which model?

A possible template to build the European Living Will Pass may be represented by the European Certificate of Succession established by Regulation (EU) No 650/2012 to settle the cross-border succession in a certain, speedy and less costly manner.

Namely, by showing a uniform certificate, heirs, legatees, executors of the will or administrators of the estate can demonstrate their status.

⁸ <https://www.sciencedirect.com/science/article/abs/pii/S2445424921000121#!>

⁹ A formal Advance Directive signed before a notary, a civil officer or a witness, is required in only 7 countries. The designation of a patient's attorney for health matters is regulated in 11 of the countries. There is an Advance Directives Register in 3 countries, whereas in the other countries it is only included in the medical record. Regular revision of an advance directive document, to maintain its validity, is required in 5 countries.

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Likewise, in a long term perspective, we advocate for a unique technology at the EU level that may be quickly accessible and prevent litigation and delays.

NEXT STEPS

- To join the initiative for a European Living Will Pass, please contact:
Johannes Agterberg johagterberg@gmail.com
Carla Pisi carla.pisi@associazionelucacoscioni.it
Virginia Fiume virginia.fiume@eumans.eu
- To take part in EUMANS ***“Citizens Congress For Democracy and Sustainability”*** and to engage in participatory democracy-based initiatives on End of Life Decisions, please contact:
Virginia Fiume virginia.fiume@eumans.eu