

**JOINT DECLARATION ON THE PROMOTION AND THE  
ENFORCEMENT OF CANCER PATIENTS' RIGHTS**

Approved by the Association of European Cancer Leagues  
(ECL) in Oslo on June 28<sup>th</sup> 2002

**PREAMBLE**

The contracting parties,

Taking into account that the modern medicine is currently increasingly complex, changes rapidly and that the relationships between patients, health professionals and health care institutions undergo significant changes,

Recognising that in the same time the patient aspires to be not only a user but an active partner in the dealing with health professionals and health care institutions by asserting the patients' rights,

Being convinced that the evolution of the medical technologies and of the administrative environment affecting the relationships between the patient, the health professionals and health care institutions requires a response from the law,

Recalling that as far as the patients' rights are legislated they are often included in a series of laws of different scope and nature, which makes difficult for the patients to learn about their rights,

Aware that this difficulty for the patient is acute when no legal specific provisions do exist or when the provisions lack legal force,

Recognising the existence of a number of policy trends and normative initiatives in the European countries demonstrating by that way a common interest in the patients' rights,

Realising that the increasing interest in the patients' rights in the general public can favour further development and involvement by the legislator,

Convinced that the adoption of a common instrument by the parties sharing common values could be particularly opportune and useful to recognise patients' rights at national and international levels,

Being of the opinion that the potential considerable benefits for the position of the patient through the adoption of a common instrument could raise consciousness about the importance of further progress and provide motivation for further improvement among others by the legislators,

Being convinced that the present instrument could help the legislators in adopting the convenient legislations or updating those available,

Considering that the promotion of patients' rights can not be isolated from its enforcement and that patients' rights must therefore be safeguarded in various ways,

Reaffirming the importance of efficient procedures for the protection of the patients in concrete situation especially when the texts are formulated in general terms,

Being determined to take all possible steps to promote and enforce the patients' rights,

Guided by the principles and provisions concerning patients' rights as established in the following intergovernmental instruments: Universal Declaration of Human Rights (1948), International Covenant on Civil and Political Rights (1966), International Covenant on Economic, Social and Cultural Rights (1966), European Convention on Human Rights and Fundamental Freedoms (1950), European Social Charter (1961) as well as Declaration of Amsterdam on the promotion of patients' rights in Europe (World Health Organisation, 1994), the Convention of Human Rights and Biomedicine (Council of Europe, 1997) and the Charter of Paris against Cancer (2000)

Have agreed upon the following provisions,

### **Article I : Definitions**

The term of patient is used in these provisions with the meaning of "user of a health care service whether healthy or sick".

The term of "cancer patient" is used with the meaning of "user of a health care service when suffering from cancer disease or problems caused by cancer".

### **Article II : Human values and rights**

- 2.1. The human values and rights expressed in the international instruments cited in the preamble shall be reflected in the health care system and especially in the relationships between patients, health professionals and health care institutions.
- 2.2. In this framework, all the patients have the right to quality of life, physical and mental integrities, to dignity, to respect of their privacy, to have their moral, cultural, philosophical, ideological, religious values and ideas respected, not to be discriminated.

### **Article III : Right to medical care and treatment**

- 3.1. Cancer patients have the right to equity of access to treatment.
- 3.2. Medical and psychosocial aspects are equally related to cancer patients. The cancer patients, their relatives and their family need counselling, support and special care during and after the treatment.
- 3.3. Cancer patients have the right to an appropriate quality of care which is marked both by high technical standards tempered by the available resources, by levels of clinical training available and clinical standards applied in any given countries and at any given time and by a humane relationship between cancer patient and health care providers.

- 3.4. Cancer patients have the right to receive the necessary health care focused on health needs, including preventive care and rehabilitation.
- 3.5. Cancer patients have the right to choose freely and change their health professionals and health care institutions in accordance with legal provisions for some categories of patients.
- 3.6. Cancer patients have the right to ask for the opinion of another health professional at any stage.
- 3.7. Cancer patients shall always be treated in the respect of their best interests according to the medical principles and the available technologies.
- 3.8. Cancer patients have the right to continuity of such care inside one hospital, between hospitals and between hospitals and homecare.
- 3.9. Cancer patients have the right to relief of their suffering according to the current state of knowledge and they have the right to humane terminal care as well as to die in dignity

#### **Article IV : Right to information**

- 4.1. Cancer patients have the right to be fully informed about their health status including the medical facts about their condition; about the proposed medical procedures, together with potential risks and benefits of each procedure; about alternatives to the proposed procedures including the effect of non-treatment and about the diagnosis, prognosis and progress of treatment.  
These informations must make the informed consent possible as a prerequisite for any medical act, participation in research and/or in teaching of medicine.  
The right to be informed is also valid for any participation in scientific research and teaching of medicine.
- 4.2. Information must be communicated in an appropriate way to the cancer patients in order to be understood, and the health professionals must ensure that the dialogue is carried out in good faith.
- 4.3. Cancer patients have the right not to be informed at their explicit request.
- 4.4. Cancer patients have the right to choose who, if any one, should be informed on their behalf.
- 4.5. Cancer patients have the right to be informed of the identity and professional status of the health professionals especially when they are admitted in the health care institutions. In that case, the cancer patients have the right to be informed on the rules governing their admittance and stay in those health care institutions.

### **Article V : Right to self-determination**

- 5.1. Cancer patients have at any given time the right to self-determination for any medical act and for participation in scientific research and in teaching of medicine.
- 5.2. When the cancer patient is legally incompetent, the consent of a legally entitled representative is required although the cancer patients must nevertheless be involved in the decision-making process to the fullest extent which their capacity allows.  
If the legal representative refuses to give consent and the health professional is of the opinion that the medical act is in the interest of the cancer patient, the final decision must be taken in accordance with legal mechanisms.
- 5.3. If a legally competent cancer patient is unable to give informed consent and where there is no legal representative or representative designated by the cancer patient, the decision-making process must take into account what is known and, to the greatest extent possible, what may be presumed about the wishes of the cancer patient.

### **Article VI : Right to confidentiality and privacy**

- 6.1. All information about a cancer patient's health status, medical condition, diagnosis, prognosis and treatment and all other information of personal kind must be kept confidential.
- 6.2. Cancer patients have the right of access to their medical files and technical records and to any other files and records pertaining to their diagnosis, prognosis, treatment and care and to receive a copy of their own files, records or parts thereof.
- 6.3. Confidential information can only be disclosed if the cancer patients give explicit consent or if expressly provided for in the law among others in case of research projects. Consent may be presumed where disclosure is to other health care professionals involved in the cancer patient's treatment or follow-up but must happen on a strictly "need to know" basis.
- 6.4. All identifiable patient data must be protected in an appropriate way.
- 6.5. Cancer patients have the right to require the correction, completion, deletion, clarification and /or updating of personal and medical data concerning them which are inaccurate, incomplete, ambiguous or outdated, or which are not relevant to the purposes of diagnosis, prognosis and treatment and care.

### **Article VII : Right to social support**

The life of the cancer patients is often connected during and after treatment with financial and economical concerns. Cancer patients and their relatives have the right to get economic, financial and social services and support as well as education and job chances.

### **Article VIII : Patients' responsibilities**

- 8.1. Cancer patients have the responsibility to participate actively in their diagnosis, prognosis, treatment and care among others by providing the health professionals and the health care institutions with the required information.
- 8.2. Cancer patients must ensure that the dialogue with health professionals and health care institutions is carried out in good faith. \_

### **Article IX : Complaints**

Patients must have access to information and advice enabling them to exercise their rights set forth in this document. Where the rights have not been respected they should be enabled to lodge a complaint. In this framework, there should be independent mechanisms and procedural methods of asserting rights through litigation or alternative forms outside the courts.

### **Article X : Application**

- 10.1. The exercise of the rights set forth in this declaration implies that appropriate means are established for this purpose.
- 10.2. The exercise of these rights shall be secured without discrimination. In the exercise of these rights, patients shall be submitted to such limitations compatible with human rights instruments and in accordance with a procedure described by law.
- 10.3. If cancer patients cannot avail themselves of the rights set forth in this document, these rights should be exercised by their legal representative or by a person designated by the cancer patient for that purpose; where neither a legal representative nor a personal surrogate has been appointed, other measures for representation of those cancer patients should be taken.



## About ECL:

The association of European Cancer Leagues is a federation of national and regional Cancer Leagues, made up of patients' coalitions and cancer control's professionals. ECL is located in Brussels and is a non-for-profit association, under Belgian law.

It was created in 1980 and consists of 34 members, located over extended Europe. Our members join forces to provide support to cancer patients, their relatives and improve the quality of treatments.

All together, the leagues spend more than 120 Million Euro to fight cancer, with a total staff of about 2,500 people and over 200,000 volunteers. Most of their budgets are spent in Patients' care, Prevention and Research.

**The objectives** of the association are to improve communication, to promote, enhance and co-ordinate collaboration between European leagues/societies and to foster fruitful activities between European cancer leagues and organisations, which are members of the ECL, in order to reduce the growing cancer burden in Europe.



## What we do:

- ❖ Information and Prevention campaigns
- ❖ European Union: Advocacy and monitoring
- ❖ Consider and recommend policy positions in various cancer related fields
- ❖ Tobacco Control: advising and influencing EU decision makers for tobacco control legislation
- ❖ Build network of cancer leagues professionals to exchange best practices and tips
- ❖ Propose guidelines and advice to develop and implement innovative plans

To achieve its missions, ECL organises, manages or develops:

- workshops
- technical meetings
- joint projects with organisations having similar aims
- exchange of information material
- set up working groups

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