

# **A Proposal for the Declaration of Rights** *of children and young patients with cancer and survivors*

## **Introduction**

**T**he Foundation "Jóvenes Contra el Cáncer – Ecuador", organized the First International Meeting of Young Patients with Cancer and Survivors in February 2010. This meeting gathered together 112 warriors from 12 countries and 4 continents. As a result of this event, the young people identified the need to create a proposal for the declaration of rights of children and young oncologic patients worldwide.

In consequence, the 1st World Convention of Young People with Cancer was held in Ecuador from May 3rd to May 8th 2012. This convention gathered together 148 young patients and survivors with cancer between 13 and 30 years old from 14 nations including countries such as: Ecuador, Venezuela, Mexico, Colombia, The United States, Chile, Canada, Peru, Bolivia, Costa Rica, Spain, Argentina, Morocco and Lithuania (Sarunas Narbutas, member of the board of directors of the European Cancer Coalition, which gathers 300 cancer organizations). The participants had a series of activi-

ties, workshops and working tables in order to set up their rights and duties based on their experiences as Cancer patients. This major event was supported by an organizational and academic committee consisting of professionals in the areas of oncology, psychology, law and organizations that support infant and young patients. Furthermore, the suggestion made by the ICCPO (International Confederation of Childhood Cancer Parent Organizations) was taken in consideration in order to incorporate the children population in this proposal, considering that many of our young patients were diagnosed during their childhood.

The main goal of this Convention was the development of a proposal for the declaration of rights of children and young patients with Cancer all over the world in order to submit it to the National Governmental authorities as well as to the representatives of the attending countries with the purpose of socialize them with the UICC, ICCPO, OMS and OPS.

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#### **Article 4. Rights during hospitalization.**

- 4.1. We have the right to be always accompanied, either by our parents, tutor or the person who replaces them, or the person we choose as long as the treatment's protocol allows it, being treated with respect and consideration.
- 4.2. We have the right to be hospitalized in specialized and suitable areas for children or young patients that allow us to spend time and identify ourselves with other patients of similar ages and interests.
- 4.3. We have the right to refuse treatments to be used as medical research, placebos and any physical or psychological suffering that can be avoided with medical care.
- 4.4. We have the right to have at our disposal, during our permanence in the hospital, playful and didactic material in accordance with our age. Such material must be free from any danger that could affect our health or our treatment in any way.
- 4.5. We have the right to be treated, during or permanence in the hospital, by an interdisciplinary and qualified personnel
- 4.6. We have the right to have access to formal education that must be endorsed by the corresponding regulatory authority from our country during the whole process of our disease.

#### **Article 5. Right to receive palliative care.**

- 5.1. We have the right to receive integral and continuous palliative care after a diagnosis about the advanced disease in an specialized and proper area either in public or private hospitals.
- 5.2. We have the right to receive an integral treatment in order to relieve pain as well as continuous physical and psychological support in case of end-stage patients
- 5.3. We have the right to die with dignity and that our will of letting the death process follow its natural course in the end-stage of our disease
- 5.4. We have the right to safeguard dignity during the last stage of our life to ensure a quality life through care and medical care which are necessary to do so.
- 5.5. We have the right to be guided to know how to face the last stage of live and to draft a living will that guarantee us not to be victims of therapeutic obstinacy.

#### **Article 6. Right to work.**

- 6.1. We have the right to be included into the work environment without being discriminated for our disease or its side effects.
- 6.2. We have the right to receive support, professional training and labor inclusion.
- 6.3. We have the right to be included in health programs, public or private social security without being discriminated for any previous Cancer diagnosis.

#### **Article 7. Rights of the survivors.**

- 7.1. We have the right to receive integral medical care that diagnoses and treats any side effects produced by any cancer treatment that could appear at medium or long term.
- 7.2. We have the right to a careful and integral treatment in case of relapse.
- 7.3. We have the right to receive continuous physical rehabilitation if necessary that guarantees a quality of life.
- 7.4. We have the right to be treated equally in our social, educational and working environment without being subjected to discrimination because of our clinical record.
- 7.5. We have the right to participate in support groups and other activities with other survivors in order to achieve academic, emotional, professional and social development.

### **SECOND CHAPTER : SPECIAL RIGHTS (patients with legal capacity)**

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#### **Article 8. Rights of decision**

- 8.1. We have the right to sign an express declaration (living will) in order to make known all our wishes for medical treatment at the end of our lives, with specific instructions for doctors not to use treatments or life-prolonging procedures, such as mechanical ventilation, cardiopulmonary resuscitation, intensive care, dialysis or artificial nutrition and hydration, this statement will be effective when:
  - We have no ability to make our own decisions and also it is not reasonably likely to regain such capacity.
  - We are at a stage of agony or termination of life or persistent vegetative state.
- 8.2. We have the right to appoint a person to make decisions for us when we cannot do it for ourselves (substitute for decision-making).



**The following provisions were agreed:**

## **FIRST CHAPTER: GENERAL RIGHTS**

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### **Article 1. Right to have access to medical treatment.**

- 1.1. We all children and young people with Cancer are the same before the Law and health public and private policies; therefore, we must benefit from the same rights and opportunities.
- 1.2. We have the right to get the most proper and prompt medical treatment without any restrictions regardless of race, gender, sexual preference, political trend or socioeconomic conditions.
- 1.3. We have the right to choose freely the health care professionals we want as well as the health institutions that provide us our required treatment.
- 1.4. We have the right to privacy and confidentiality of our disease and medical treatment; only with a previous consent we can waive such rights.
- 1.5. We have the right to have an immediate treatment in case of emergency in any health care public or private establishments in the world without any restrictions of prepayment or guarantee or conditioning as well as nationality or immigration status.
- 1.6. We have the right to look for a second medical opinion, and this must not generate discrimination or rejection from the physician or institution where the diagnosis was done.
- 1.7. We have the right to participate actively in the decision making about our treatment especially when it includes any radical or mutilating behavior.
- 1.8. We have the right to have a timely diagnosis, scanning, medical lab, nuclear medical scans or any other tests in our initial diagnosis and during the monitoring.
- 1.9. We have the right to receive regular medical thorough checkups, appropriate in relation to the diagnosis and health condition.

### **Article 2. Right to receive an integral treatment.**

- 2.1. We have the right to be treated at the Oncology Services or Units of children and youth located in oncological and general hospitals with a qualified interdisciplinary team of doctors including specialists devoted to the health care of oncology pediatric patients.
- 2.2. The Oncology Units of children and youth must comply with the international infrastructure and operational standards.
- 2.3. We have the right to receive support in our socioeconomic needs in order to have access to specific health care services and rehabilitation according to our disease needs.
- 2.4. We have the right to be evaluated by an interdisciplinary team of health care professionals so that it can guarantee a proper cancer diagnosis and treatment.
- 2.5. We have the right to receive a dignified treat, that respects our ideologies, beliefs and customs.
- 2.6. We have the right to be treated as human beings and be called by our names and not be denominated with the name of a determined pathology.
- 2.7. We as well as our families have the right to receive a specialized psychological assistance that supports us emotionally during the whole disease process.
- 2.8. We have the right to receive or reject spiritual or moral support during all the stages and moments of the disease and of the treatment.
- 2.9. We have the right to receive any kind of support that helps us to develop our personal abilities and skills.

### **Article 3. Right to have information about their disease.**

- 3.1. We have the right to receive proper and trustworthy information in a confident environment where the most qualified personnel must be present to support us if necessary
- 3.2. We have the right to receive reliable and complete information about our diseases and treatment, this information must be professionally adapted to our age, affective stage, emotional and psychological condition. We must know the benefits and collateral negative consequences that our medication can generate.
- 3.3. We have the right to know the identity and professional training of all the members of the interdisciplinary group that will be in charge of our cases.
- 3.4. We have the right to be part of the decision making regarding our disease and treatments.
- 3.5. We have the right to create support groups for people with similar health experiences.
- 3.6. We have the right to be informed about the most appropriate, supporting, integral and complementary treatments,
- 3.7. We have the right to be informed about the national and international treatments and protocols.