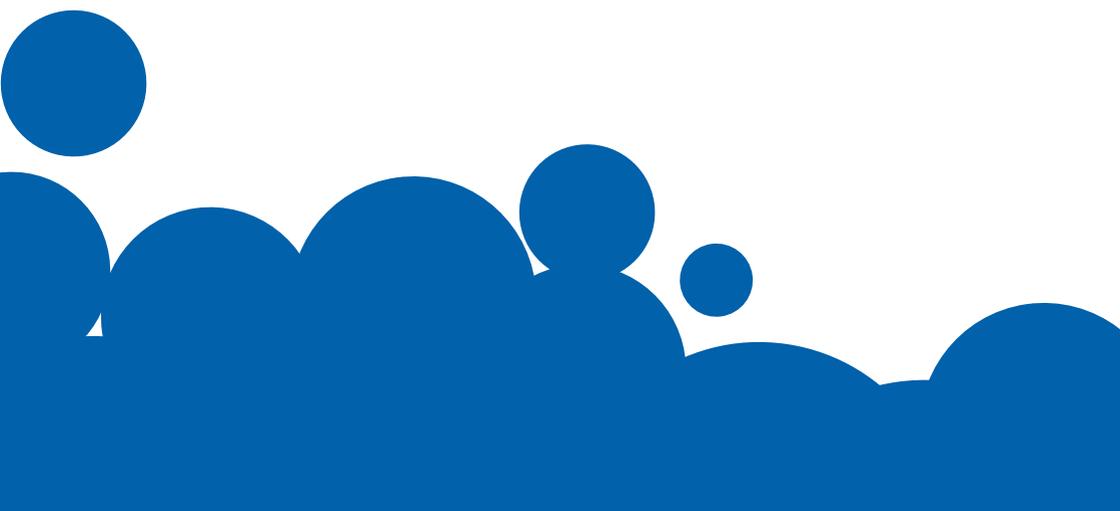




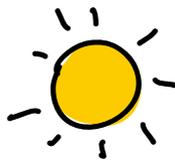
Bambino Gesù
OSPEDALE PEDIATRICO



OF THE INCURABLE CHILD



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Background

Almost thirty years after its approval by the General Assembly of the United Nations on 20 November 1989, the U.N. *Convention on the Rights of the Child*, together with the European *Charter on the Rights of the Child* (Resolution of July 8, 1992, of the European Parliament), are still the fundamental reference sources for the rights of minors in Europe and in 196 countries.

Research studies on the needs of children in hospital, inspired by the work of James Robertson *Young Children in Hospitals* (1958), and by Giuliana Filippazzi's *Un Ospedale a misura di bambino* (A Child-sized hospital) (1997), have underlined the need to dedicate special attention to the particular needs of hospitalized children.

At the same time, the European Parliament Resolution of 8 July 1992 found application in the Charter prepared by the European Association for Children Hospital (EACH), merging together two previous documents: the 1986 European Charter for Children in Hospital, and the 1988 Charter of Leiden. The EACH Charter still is the main reference source in this field, shared by 22 organizations in 18 countries of the European Union.

In Italy, the *Carta dei Diritti del bambino in Ospedale* (Charter of Rights of the child in Hospital) adopted by the *Associazione Ospedali Pediatrici Italiani* - AOPI, (Association of Italian children's hospitals), is the result of the joint effort of four Italian children's hospitals, and was then accepted by all the other children's hospitals belonging to AOPI (first edition 2005, latest update 2014).

Another Italian experience in this domain is the *Carta dei diritti dei bambini e degli adolescenti in Ospedale* (Charter of the Rights of Children and Adolescents in Hospital), published in 2008 by Fondazione ABIO and *Società Italiana Pediatria* – SIP ("Italian Society of Pediatrics"). In order to implement the principles contained in these Charters, the

children's hospitals at first, and then ABIO-SIP together with PROGEA drafted and distributed Manuals of Voluntary Accreditation for the verification of these principles' application.

The *Charter of the Rights of the Dying Child*, also known as the Trieste Charter, is the result of an initiative promoted in 2012 by the Foundation *Maruzza Lefebvre D'Ovidio*. It was presented by the Italian Minister of Health, and the *Autorità Garante per l'Infanzia* (Authority for the protection of children) undertook to diffuse it in Italy.

There are several other European and Italian initiatives in this domain, all of them inspired by the 1989 Convention. A project of particular significance is the one developed by the task force of the WHO network of Health Promoting Hospitals (HPH).

Moreover, EU directive 2011/24 (Application of Patients' Rights in Cross-Border Health Care) recognizes to all European citizens the right to receive healthcare in all countries of the European Union, with the possibility to choose the healthcare professional and facility, for elective or urgent treatment, without needing a prior authorization.

In Italy, Law no. 219 of 22 December 2017, "on informed consent and arrangements prior to treatment" establishes that no treatment can be initiated or continued without a free prior informed consent of the patient, thus encouraging the care relationship between patient and doctor/healthcare personnel, and also including the patient's family.



Introduction

The medical advances in the last decades and the development of social protection systems have allowed to prevent and cure several diseases, but - at the same time - have contributed to the transformation of acute diseases into chronic diseases. Rare diseases, adult congenital patients, and chronic diseases represent the new challenges of pediatric healthcare.

Parallely, there has been an increase of diseases associated with environmental factors, behavioral factors, and life style (accident traumas, allergies, obesity, metabolic and cardiovascular diseases), and of psychosocial disorders (foreign minors, handicapped minors, and situations of social distress).

In this new scenario, the concept of “treatability” as an alternative to “curability” for an ever increasing number of patients (in particular pediatric patients) has acquired a new meaning, also involving the patient’s family in the treatment process.

On the other hand, transboundary healthcare has widened the frontiers of healthcare, and the internet allows to establish immediate contact with the best health facilities in the world.

Given this evolving scenarios, it is important to reconfirm the rights of and try to apply them to this new reality.

This *Charter of Rights of the incurable child* may be proposed as an update of the EACH Charter and the other charters, with the aim of including fragile children with special needs, with chronic diseases, who may not have the possibility of being cured, but who deserve receiving care, even in the end-of life phase.



The child and family have right to the **best relationship** with medical and healthcare staff

The therapeutic alliance between family and doctor is a fundamental element in the child's care process.

The communication process between child, family and healthcare staff should be an exchange, based on human respect and guided by the common goal to achieve the highest possible level of wellbeing and protect it, avoiding conflicts or discordance.

The time spent for communication between doctors and patients is part of the care process. The main instrument of this relationship is Informed Consent. All hospitals should provide their staff with training on communication techniques, information-sharing, and supervision methods. The effectiveness of this training should be measured.

Defense of life, protection of physical and mental health, and relief from pain shall be the constant responsibilities of the medical staff, within a relationship of trust, respect and discretion.

In case, despite every effort, no agreement can be reached between the patient's family and the medical staff on some specific questions, such questions may be submitted to the Ethics Committee.





The child and family have right to **healthcare education**

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The child and family must be helped acquire and maintain abilities allowing them to understand the disease and its treatment, collaborate with the healthcare staff, and maintain or improve their quality of life.

The healthcare staff shall be responsible of providing the appropriate education to the child and family, based on the best available scientific evidence and medical competences.

Therapeutic education must be provided by specifically trained staff. Hospitals must encourage projects on family-centered care, entailing the direct involvement of families in the process of care, and projects of narrative medicine, based on listening ability and experience sharing.

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The child and family
have the right to obtain
a **second opinion**

The child and family have the right to request and obtain in-depth information, and a second opinion from other experienced professionals or institutions on a diagnosis or a treatment.

Treating medical staff must inform patients of their right to request a second opinion and on the relevant operational modalities, and they must facilitate the external consultation (either on-line or in person) and offer the necessary support.

Medical staff have the responsibility to understand the reasons leading to the request of a second opinion and to try to resolve any conflictual situations. Moreover, they must enter the relevant information into the patient's clinical record.



The child and family have right to the best **in-depth diagnostic process**

Children have right to the maximum level of care, aimed at ensuring their best option of survival and development.

The child and family have right to receive information of other medical facilities, even at the international level, having greater experience and qualifications, and to consult with these facilities.

Hospital must guarantee patients' right to all necessary investigations to define a diagnosis, including predictive and preventive genetic testing, in agreement with the treating medical team and within the limits of available resources.



The child has right to have access to the best available **experimental treatment**

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The child has right to have access to diagnostic/therapeutic experimental protocols approved by the Ethics Committees within clinical trials conducted in compliance with the Good Clinical Practice (GCP), adopted by the European legislation.

Any risk factors associated to experimental treatments/procedures to minor patients must be excluded or reduced as much as possible.

All medical and surgical procedures, including experimental procedures, cannot be performed without the prior informed consent of the child's parents or legal guardians. Children must be informed in the most appropriate way for their age and should accept the treatment without feeling obliged to.

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The child has right to **transboundary healthcare**

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Every family has the right to choose, for the best interest of their child, the doctor, medical staff and medical facility they consider as more appropriate for their child, also when this entails the transfer to another country.

Hospitals shall respect the right of the child and family to choose the doctor and medical facility they deem appropriate, even within the framework of transboundary healthcare.

The right to go to another country to receive medical treatment might be limited by national legislations only for reasons of general interest and/or when this may affect the rights and freedom of other people.

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The child has right to continue care and **palliative care**

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The child has the right to be hospitalized in pediatric wards, and, whenever possible, to receive home-based care.

Hospitals shall assess patients' clinical and social needs using the appropriate multi-disciplinary tools in order to define a personalized treatment plan.

The child has the right to receive appropriate treatment for both psychological and physical pain. Symptoms and pain must be prevented whenever possible and always alleviated. Palliative care should be included in the treatment planning to complement the therapeutic and rehabilitation program.

Quality palliative care requires specific professional skills.

Continuity of care should be guaranteed to non self-sufficient children, with chronic, progressive and/or incurable diseases, through residential care facilities, such as the Pediatric Hospice, with specific plans of care consisting of the combination of medical, nursing, rehabilitation, spiritual and social care.

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The child has the right to be **respected as a person** even in the end-of-life phase, refraining from therapeutic obstinacy

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Extremely fragile children - including incurable and end-of life diseases – have right to medical, nursing and support care (psychological, social, spiritual), based on their specific conditions, avoiding both unreasonable therapeutic obstinacy, and voluntary anticipation of death.

Care does not always mean cure. The caring bond between parents and child is fundamental in the process of care. Taking care of children entails taking care of their whole family.

The caregiving relationship between parents and child must be supported with all available means, also when the disease is incurable or terminal.

Cure, treat, care and accompany/support are progressive steps of the therapeutic process.

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The child and family have right to **psychological and spiritual support**

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The child and family must be given support in the “elaboration of the disease”, including incurable and progressive diseases, always considering, in addition to their clinical needs, their emotional, psychological and spiritual necessities.

In addition to the work of medical and nursing staff, families have right to professional help by psychologists, social workers, educators, counselors, and spiritual assistants to support and orient them during the critical period of the disease.

Close relatives and friends should be given the possibility to visit the patient and family as frequently as possible.

The hospital staff must ask the child and family if they feel the need for spiritual assistance, and ensure the presence of a Minister of the chosen religion.

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The child and family have right to **participate** in the hospital research, healthcare and hospitality activities

The child and family have the right to be involved and consulted in the hospital decision-making both in healthcare and organizational matters. The child and family have the right to be involved in the hospital healthcare, research and hospitality activities, and their active participation in the Hospital Committees and Parents' Associations should be encouraged.

A training to become “*expert patients*” in the different chronic diseases should be promoted, in order to spread knowledge, and stimulate the involvement and direct participation of patients and families in the process of care, as well as in research activities and clinical trials on new drugs.

A colorful illustration featuring a sun, clouds, and five children. Four children are jumping joyfully, and one child is being held by a doctor in a white coat. The scene is set against a blue background with small flowers and grass tufts.

Charter of Rights

OF THE INCURABLE CHILD



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