

# Declaration of general and special rights of persons with Epidermolysis Bullosa

**Recalling** the principles proclaimed in the Universal Declaration of Human Rights which recognize the inherent dignity and worth and equal and inalienable rights of all members, of the human family as the foundation of freedom, justice and peace in the world,

**Recalling** the United Nations Convention on the rights of the Child, stating that a mentally of physically disabled child should enjoy a full decent life in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community,

**Recalling** the Convention on the Rights of Persons with Disabilities which promotes, protects and ensures the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and promotes respect for their inherent dignity,

**Recalling** the Optional Protocol to the Convention on the Rights of Persons with Disabilities which highlights that State Parties to this Protocol recognize the competence of the Committee of on the Rights of Persons with Disabilities to receive and consider communications or on behalf of individuals subject to its jurisdiction who claim to be victims of a violation by that State Party of the provision of the Convention.

## Article I Purpose

The purpose of the present Declaration is to ensure that persons with Epidermolysis Bullosa have the same basic rights as any other person regardless of nationality, ethnicity, religion, age, race or gender; States shall adopt appropriate legislature and other measures to achieve those ends.

## Article II General Principles

- a. Right to respect;
- b. Right to care;
- c. Right to family life;
- d. Right to be an active member of the community;
- e. Right to a decent standard of living and economical security;
- f. Right to legal employment;
- g. Right to protection in abuse situations and positive obligation to protect the right of persons with Epidermolysis Bullosa.

## Article III

1. Persons with Epidermolysis Bullosa have the right to be respected like any of person.

## Article IV

1. Persons with Epidermolysis Bullosa have a right to proper medical care, rehabilitation, education and guidance;
2. States shall adopt appropriate measures to ensure this;
3. No person with Epidermolysis Bullosa should be deprived of such care by reason of the costs involved;
4. This is necessary in order to ensure that such a person have an Equal chance to enjoy a decent life.

## Article V

1. Persons with Epidermolysis Bullosa have a right to live with their own family;
2. Persons with Epidermolysis Bullosa should also be entitled to a foster family with their direct family cannot give them a normal family life. For example, where persons with Epidermolysis Bullosa are abused or neglected by their family, they have the right to live with a foster family.

## **Article VI**

1. Persons with Epidermolysis Bullosa have a right to participate in all aspect of community life;
2. Wherever possible, Persons with Epidermolysis Bullosa should be involved in as many social, economic and political events within their community as other people;
3. This is important to ensure that persons with Epidermolysis Bullosa are given the chance to have a normal life to the extent that this is possible given their disability.

## **Article VII**

1. Persons with Epidermolysis Bullosa have a right to economic security and to a decent standard of living;
2. In cases where persons with Epidermolysis Bullosa are unable to work to maintain a decent standard of living due to the severity of there disability and / or are not financially supported by a third party, States shall ensure that these financial shortcomings are met to ensure a decent standard of living.

## **Article VIII**

1. Persons with Epidermolysis Bullosa have the right to an legal employment of any legal occupation;
2. Persons with Epidermolysis Bullosa have the right equally fair chance of getting a job as any other person;
3. Persons with Epidermolysis Bullosa are not to be discriminated against in the work place.

## **Article IX**

1. Persons with Epidermolysis Bullosa have a right to be protected from abuse and degrading treatment. If a person with Epidermolysis Bullosa alleges to have been abused, the victim and the perpetrator have a right to a fair trial.

## **Article X**

Persons with Epidermolysis Bullosa are aware of their rights. For this reason, States, Institutions, Employees of persons with Epidermolysis Bullosa and other persons, have a positive obligation to enforce these rights.

**Above all The Person with Epidermolysis Bullosa has the Right to Respect**

**Debra International**

**Global Network or Epidermolysis Support Groups**

October 2011

<http://www.debra-international.org>