

## THE PROBLEM

Haemophilia is a hereditary disease, which strikes about one in 10,000 people. Its typical symptom is haemorrhage caused by the lack of a blood coagulation factor.

Treatment options mainly centre on administering concentrates of the lacking factor produced as plasma derivatives or by genetic engineering methods.

Health care is guaranteed by a network of specialized centres. Treatment at home can be organized by training patients or their relations.

**A well cared haemophiliac can live a full perfectly "normal" life today.**

Therapeutic resources have undergone a considerable increase these past ten years. If the prospects of a healing genic therapy still seem uncertain, constantly perfected recombinant drugs, which are now more or less free of human and animal proteins both during the preparation stage and in the final formula, have ensured patients and their families the safety they had never known so far. Besides products designed to have a longer half life in the body – a feature that would greatly facilitate prophylaxis – have reached an advanced stage of study.

# The Organizational Framework

## THE FEDERATION

Formed in 1996, the Federation of Haemophiliac Associations is a voluntary organization.

It combines the cultural heritage and commitment to protect the rights of haemophiliac patients formerly expressed by the Italian Foundation since 1969.

The Federation is a non-profit organization of public interest. Its main statutory duties are listed below:

- work towards solutions for the medical and social problems of haemophiliacs in Italy;
- coordinate, support and represent local associations related to the world of haemophilia;
- promote activities targeted at strengthening scientific research in the sector of blood coagulation diseases and genic therapy.

The Federation's members currently count 29 local associations, which globally represent the approx. 8,000 Italian haemophiliacs and individuals suffering from congenital coagulation diseases [Source: national register of the Italian National Institute of Health (*ISS - Istituto Superiore di Sanità*)].

## INITIATIVES

The Federation has successfully made relevant progress since it was formed.

It has contributed to distributing drugs produced by recombinant DNA technology available in Italy and towards better legal provisions concerning biological damage (Law Nos. 210/92 and 238/97).

The Federation collaborates with physicians and scientists committed to treating haemophilia (Italian Association of Haemophilia Centres), also participating in the organization of the Triennial Conference on Clinical and Social Issues.

It is recognized as representative of haemophiliacs by the most relevant institutions, especially in their relations with the Ministry of Health (the National Committee for Blood Transfusion, the National Council for Aids, the Joint Committee for compensation for damage caused by blood transfusion).

In the international framework the Federation is a member of the WFH (World Federation of Hemophilia) as a national member organization and of the EHC (European Haemophilia Consortium).

It handles communications targeted at haemophiliacs and their families through a newsletter and the website [www.fedemo.it](http://www.fedemo.it).

The Federation also promotes patient counselling and information through the secretariats of Milan and Rome-based member associations.

It has encouraged the formation of a work group specialized in spreading information on genic therapy and healing prospects.

# Actions

In recent years it has launched and coordinated many projects focused on overall treatment for haemophilia.

## PUER

Training and supportive programme for parents and young haemophiliacs.

## SPRINT

A series of meetings targeted at patients on the theme "Haemophilia, sports and rehabilitative therapy".

## CTO

Project targeted at ensuring haemophilic patients a better welcome and integrated medical, surgical and rehabilitative care in the orthopaedic sector.

## HAEMOPHILIA AND RESPONSIBLE PROCREATION

A detailed study on the issue of genetics and responsible procreation. This project is not focused on proposing solutions, but rather on attracting the attention of people suffering from haemophilia and their relations to enable them to face the important decision of having children in an informed and hence fully responsible manner. This prospect becomes crucial when there are viral problems.

## PROJECT DISCLOSURE

Campaign focused on spreading knowledge and information to sensitize public opinion at large on haemophilia's most basic mechanisms, to sensitize local and central health administrations and to bring a larger number of specialists closer to the world of haemophilia.

From its formation to date the Federation has had to face the problem of blood borne infections. In 2004 civil cases promoted with the Federation's collaboration reached legal settlements thanks also to political lobbying conducted by the same Federation, which is considered a guarantor by the Ministry of Health.

Besides, at the close of 2003 the Federation established a solidarity fund for haemophiliacs suffering from HIV infections – an initiative that has already been implemented in many countries. The Paracelso Foundation was formed in the agreement's framework. Its statutory goals are to back scientific research and social activities to benefit the Italian community of haemophiliacs.

In the international framework, the Federation has encouraged an agreement between the Lombardy Regional Administration and the Russian region of Nizni Novgorod, distributing large quantities of nationally produced factor VIII free of charge. On many occasions it encouraged the donation of products, which were then channelled mainly towards the care of children in Romania and Morocco."

Members in the Board of Directors and work groups have agreed to carry out the initiatives and social battles on a purely voluntary basis. The Federation is financially backed by the annual subscriptions of member associations, while projects are financed by targeted contributions made by private individuals and firms.



### General Secretary:

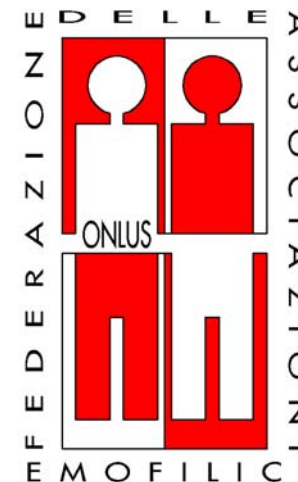
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# Federazione delle Associazioni Emofilici Onlus



*Improving the quality of life of haemophiliacs and encouraging scientific research on blood coagulation diseases is our target.*

Member of the  
World Federation of Hemophilia