

# **“HHT EUROPE – Federation of Patient Organizations Onlus”**

## **Statutes**

### **TITLE I**

#### **General Information**

##### **Art. 1 Naming**

1. La **HHT EUROPE – Federation of Patient Organizations Onlus** is a non-profit organization in the field of social assistance and health care. HHT stands for Hereditary Haemorrhagic Telangiectasia. It is a rare multi-systemic disease that causes arteriovenous malformations in most organs. Such malformations tend to bleed and can cause severe complications also leading to death of the individual.
2. The Federation carries through its activities mainly through volunteers who are members of the federation.
3. The Federation is an ONLUS therefore an Organization with non-profit goals that works in the field of social benefit. This is the main characteristic of the Federation.

##### **Art. 2 Mission and Means of Action**

1. HHT Europe exclusively pursues social solidarity goals and as an ONLUS it is organized exclusively for humanitarian and scientific purposes regarding HHT. The general mission statement of HHT Europe is as follows:
  - to represent, protect and enforce rights and interests of people with HHT at a European level.
  - building a strong pan-European community of people living with HHT
  - spreading awareness of HHT
  - improving access to information, services, diagnosis, treatment and care
  - promoting the exchange of good practices
  - Improvement of treatments and knowledge of the disease in the medical community
  - Finding a cure

While the means of action can be:

- Fostering and supporting HHT Centers across Europe
- Fostering the creation of Patient Associations in European countries which do not present one.
- Co-ordinating professional expertise and exchange within Europe and Internationally
- Encouraging and fostering Joint clinical trials and research across Europe
- Promoting educational programs and training for Medical Staff and Patient Organizations

- Organizing International Congresses
  - Promoting and managing contact between HHT Organizations
  - Collecting, disseminating and translating information on HHT
  - other such things approved by the Board that will further the objects of HHT Europe.
  - Collecting data
2. The Federation HHT Europe cannot engage in activities different from the ones mentioned above unless directly connected to the Federation's mission. The brochures, letters and other communications can be translated into any other language and in any part of the world.
  3. In order to reach its goals the HHT Europe Federation can create structures or use those existing on National and International territories and pursue, if necessary, financial and commercial activities directly connected to the goals of the Federation.
  4. It is strictly forbidden to engage in activities that are not permitted in an ONLUS as by law: all'art. 10 del DLGS 460/1997,

### **Art. 3 Creation of the Federation**

1. The creation of HHT Europe is promoted by Single HHT Organizations existing in Italy and Europe.
2. In order to pursue its goals and programs and in order to be coherent with the mission, the Federation may establish relations and co-operation with other associations and public or private entities at a National, Regional or Local level. The Federation may promote or participate in the creation of foundations, study centres, cultural and scientific institutions.

### **Art. 4 Base**

1. HHT Europe is legally based - c/o Studio Muci e Associati, Via Settembrini 9, Roma – 00195. Italy

### **Art. 5 Discipline of the Federation**

1. HHT Europe is disciplined by the present Statutes, by regulations and executive dispositions and it operates in total respect of the law.

## **TITLE II**

## **Federation Membership**

### **Art. 6 Membership**

1. HHT Europe is constituted by HHT Member Associations operating in their National and European territories.
2. Membership in the federation is open to all HHT Associations that prove that the goal of their organization is social and healthcare assistance in the field of HHT and also prove to share the mission of the present Statutes of the Federation and want to contribute to reaching common goals.
3. Patient Organizations that wish to be admitted to HHT Europe must deposit a copy of their statutes and other regulations.
4. The member Patient Organizations comply to notifying HHT Europe of any change in the above documentation.
5. The Board of Directors of HHT Europe votes the admission to the Federation and if the admission is refused it must be motivated.
6. In order to be a member of HHT Europe, Patient Organizations must have a mission statement in their statutes corresponding to what is stated in Art.2 and activities in the field of Social and Healthcare assistance, a Democratic organizational structure and in no way in contrast with the executive dispositions of the Federation.

### **Art. 7 Rights and Obligations of Federated members.**

1. The Federated members must pay their annual membership fee according to what has been established by the Board of Directors of HHT Europe and they must contribute, according to their possibilities to reaching the goals of the Federation and making sure the rules of the Federation are observed.
2. The membership fee cannot be transmitted to others except when and if the Federation should be closed and cancelled as established by law: (art. 10, DLG 460/1997, lettera f)
3. All members are under the same treatment in the organization and it is not possible to have a temporary participation in the Federation.
4. The Federated members are entitled to:
  - a. Electing the members of the governance of the Federation HHT Europe and being elected.
  - b. Approve the present Statutes and eventual rules and regulations as specified in art. 10
  - c. Promote and organize activities that comply with the mission of the Federation as stated in the statutes.
5. Each Federated member is represented by its legal representative or by a delegate that will represent the organization in the Federation. This nomination and any future substitutions must be notified in written form to the Federation.
6. The Federated members who do not comply to Federation obligations can be suspended from

exercising their rights or excluded as by article. 8 and article 15.

### **Art. 8 Recesso ed esclusione**

1. A Patient Organization loses its qualification of Federated member if it does not pay the annual membership fee, if the Board of Directors of the Federation motivates an exclusion of renewal of the membership, or if the Patient Organization is expelled for behaviour or activities that are in contrast with the mission of the present Statutes.
2. An organization can withdraw from the Federation with a formal letter sent to the President of HHT Europe by return mail. The withdrawal is effective after closing the solar year.
3. Exclusion is deliberated by the Board of Directors of HHT Europe.
4. The excluded organization can appeal to the Assembly of the Federation.
5. Patient Organizations that have withdrawn or are excluded from the Federation cannot request reimbursement of membership fees or other fees and they have no rights on the substances of HHT Europe.

## **TITOLO III**

### **Federation Structure**

#### **Art. 9 Organisms**

1. HHT Europe has the following organisms.
  - a) Assembly of Federated members
  - b) Board of Directors
  - c) President
  - d) il Collegio dei Sindaci

#### **Art. 10 Assembly of Federated Members**

1. The Assembly is the main deliberating authority of the Federation.
2. All members in line with the payment of the annual membership can participate in the Assembly with right of vote and right to be voted.
3. Each organization is entitled to one vote. Each Federated organization can be represented at the assembly, with a written proxy, by another organization. Each member of the Assembly can hold a

maximum of two proxies on behalf of other organizations.

4. The Assembly can be ordinary or extraordinary:.
5. The ordinary Assembly is in charge of:
  - a) Establishing, examining and approving the specific aims, programmes and general directives of the Federation.
  - b) Approve the closing budget and proposed budget for the Federation.
  - c) Elect the members of the Board establishing the number of members and if necessary the Collegio dei Sindaci.
  - d) Deliberate on topics regarding exclusion of a member according to art.7 of the present statutes. deliberare su ogni altro argomento che il Consiglio Direttivo vorrà ad essa sottoporre.
  - e) The ordinary assembly is held at least once a year-
  - f) Approve rules and regulations
6. The extraordinary Assembly is in charge of:
  - a) Deliberating changes to the present Statutes.
  - b) Deliberate on the dissolution of the Federation and the destination of its patrimony according to art.21.
7. The date of the Assembly is communicated to members at least 30 days prior to the date of the Assembly itself with any means that allows to prove the member has received the communication including, telegram, return mail, fax, email. The letter must include date, time and place of the meeting along with the points to be discussed.
8. All assembly deliberations must comply with the law and represent an obligation for members.

#### **Art. 11 Validity of the Assembly**

1. The President of the Federation is president of the Assembly, in his absence the President is substituted by the vice president and in absence of both the Assembly nominates a President.
2. The President of the Assembly verifies the validity of the proxies and the right to speak in the Assembly.
3. The Assembly is valid upon first call if half or more of the members are present. Upon second call whatever the number of the members present.
4. All deliberations of the Assembly are approved with a majority of votes. Abstentions are not included in the count. The deliberations regarding Statute changes require the presence of the majority of the members and approval on behalf of 2/3 of the members voting in person or by proxy.
5. Dissolution of the Federation and subsequent devolution of the patrimonial assets of the Federation require approval on behalf of ¾ of the members.
6. All deliberations must be summarized in the minutes of the assembly and signed by the President and the Secretary. Each member is entitled to access the Minutes of the meetings.

#### **Art. 12 Composition and Roles in the Board of Directors**

1. The Board of Directors has the executive power in the Federation.
2. The Board of Directors is elected by the Assembly of Federated members. It is made of a minimum of 5 to a maximum of 9 members elected among the members of the Federation.
3. The members of the Board of Directors are in power for 4 years.
4. If one or more organizations cease to be members the Board substitutes them nominating the next elected member. These new nominated members finish their role along with the others at the end of the mandate. If more than half of the members pull out the President must require new elections.
5. The Board of Directors elects among its members the President, Vice President and gives the mandate of Secretary and Treasurer among its members. Each member can have two roles in the Board except the legal representative.
6. No members of the Board can receive any compensation for their activities in the Federation except reimbursement of expenses where applicable and in the limits of art. 18 of these statutes.

### **Art. 13 Board of Director Meetings**

1. The Board of Directors is convened by the President each time it is necessary and at least once a year. The Board can be convened upon request of at least two of its members.
2. Members must be informed at least 15 days prior to the meeting and the notification must contain the day, place, time and list of topics of the meeting.
3. The Board of Directors is held by the president or in his absence by the VicePresident or by the eldest of the members if both are not attending. If the Secretary of the Board is not present another person can be chosen among the members.
4. The meetings of the Board are valid when the majority of the members attend. The deliberations are voted and approved with a majority of votes that have to be specified in the Minutes of the meeting signed by the President and the Secretary.

### **Art. 14 Powers of the Board of Directors**

1. The Board of Directors carries out the program approved by the Assembly in order to reach the aims of the Federation.
2. The Board of Directors also:
  - a) Elects the President and VicePresident.
  - b) Nominates among its members the Secretary and the Treasurer.
  - c) Administers economic resources with complete power.
  - d) Prepares, at the end of each solar year, the closing budget sheet and the budget for the following year to be presented to the Assembly for approval.
  - e) Should it be deemed necessary the Board can create a set of inner rules that must respect the present Statutes and that can regulate specific aspects of the Federation. These rules must be approved by the Assembly.
  - f) Convenes meeting and conferences etc.
  - g) Deliberates on all ordinary and extraordinary administration of the Federation.
  - h) Deliberates on Federation participation in other organizations.
  - i) Decides on admission and exclusion of members.
  - j) Deliberates on hiring people or consultants to guarantee the accomplishment of the Federation mission according to law: (ai sensi dell'art. 3, comma 4, della legge 266/91);

- k) The Board of Directors must establish the date of the Assembly along with the Agenda of the meeting and send out the invitation in due time.
- l) Creates operative bases nominating people responsible for them and also with the power of removing the responsibility.

### **Art. 15 The President**

1. The President is also a legal representative of the Federation. He is president of the Assembly and of the Board.
2. The President is elected by the Board of Directors and his mandate lasts 4 years and he is re-electable for one consecutive mandate.
3. He convenes and presides the Assembly and the council of the Board of Directors.
4. Specifically the President:
  - a) Makes sure the deliberations of the Assembly and the Board become operative.
  - b) Is delegated to carry through all ordinary operations of the Federation, opening bank accounts, postal accounts, operating these accounts and other financial operations, receive payments on behalf of the Federation from any entity, make sure payments are made, pay workers.
  - c) For all bank and financial operations the Board can request that another member have power of attorney and signature on the accounts.
5. The President represents the Federation with other institutions in the territory.
6. In case of emergency or particular urgency he can also make decisions that would in other cases be made by the Board of Directors prior to having consulted with the VicePresident and with the obligation to refer the decision made under such urgency to the Board of Directors.
7. The VicePresident substitutes the President in case of absence in all of his functions.

### **Art. 16 Secretary and Treasurer**

1. The Secretary and Treasurer cooperate with the President to help in his work.
2. The Secretary must:
  - a) Write the Minutes of the meeting of the Assembly and the Board of Directors.
  - b) Convene the meetings of Assembly and Board members with the correct timing.
  - c) Be responsible for filling out the books of the Federation: book of minutes and list of members.
3. The Treasurer must:
  - a) Keep the accounting books in order.
  - b) Prepare the budgets of the Federation.

### **Art.17 Il Collegio dei Sindaci**

1. The Collegio dei Sindaci, if established, is made of three official members and two substitutes and they are elected by the Assembly with open vote even among non-members.
2. The members of the Collegio must have specific requisites of competence, honesty and

- experience.
3. The Collegio elects a President among its members who must convene the meetings and supervise the work of the Collegio. If the President should resign the Collegio must elect a new one in the following meeting.
  4. In case of death or withdrawal of one of the members the substitutes enter the group in order of age. If the substitutes are not enough the Board of Directors must integrate the necessary vacancies. If the members of the collegio become less than two the Board can nominate others. The new nominated members end their mandate with the others.
  5. The role of Sindaco of the Collegio is not compatible with any other role in the Federation.
  6. The Collegio lasts 4 years and its components can be re-elected for not more than two consecutive mandates.
  7. The members of the Collegio participate in the Assemblies and Board meetings.
  8. The meetings of the Collegio dei Sindaci is valid with the presence of the majority of the Sindaci and the decisions are approved with a majority of votes.
  9. The Collegio must keep minutes of its meetings.
  10. The Collegio:
    - a) Controls the administration of the Federation on a quarterly basis.
    - b) Verifies the accounting documents.
    - c) Presents an annual report to the Assembly during approval of budgets.
    - d) In case of severe accounting irregularities the Collegio can request the authority of the National guarantees of the National federation that will report within 60 days.

### **Art. 18 Non payed elective mandate**

1. All the elective mandates in the Federation are volunteer works that cannot be paid. Reimbursements of expenses can be made within the limits established by the Federation.
2. The elective mandates are not compatible with any form of work (direct or indirect) with the federation.

## **TITOLO IV**

### **Financial Resources**

#### **Art. 19 Assets**

1. The Assets of the Federation are composed by:
  - a) Contributions of the single members
  - b) Membership fees
  - c) State, Region, Local Authority, Public Institution contributions aimed at specific activities or projects in the respect of the Statute's mission.
    - d) EU contributions or contributions of International organisms, donations or wills.
    - e) Donations from other organizations.



- f) Resources from fundraising events.
    - g) Reimbursements
  - h) Profits deriving from sale of goods or services
    - i) Any other form of contribution compatible with an Onlus.
2. During the life of the Federation it is prohibited, even indirectly to distribute assets among the members in any form unless it is requested by law or if they are made in favor of ONLUS organizations that by structure and regulation are part of the same structure.
  3. The Federation must use all assets exclusively to reach federation goals.

#### **Art. 20 Financial year**

1. The financial year begins on January 1st and ends December 31st of each year.

#### **Art. 21 Devolution of assets.**

1. Should the Federation be dissolved because it ends its activities or for any other reason, dissolution must be approved by the Assembly with  $\frac{3}{4}$  of favorable votes.
2. In case of dissolution the assets of the federation are donated to other non-profit organizations.

### **TITOLO V**

#### **BUDGET**

#### **Art. 22 Budget**

1. For each Financial year the Board of Directors prepares a budget that outlines the fields of investment along with a report of the activities involved. This Budget must be approved by the Assembly.

#### **Art. 23 Closing budgets**

1. For each financial year the Board of Directors will prepare a detailed budget on how money was spent, along with an asset report on the activities pursued by the Federation. This budget must be approved by the Assembly.

#### **Art. 24 Budget approval.**

1. Budget and closing budget are to be presented to the Assembly of members for approval before April 30th of the year following the closing budget. All the members must receive a copy of the budgets and reports along with the announcement of the meeting. If the Collegio dei Sindaci has been created the Collegio will receive the documentation also 30 days prior to the meeting. The budgets, reports and eventual report on behalf of the collegio dei Sindaci must be deposited at the Federation premises in order for all members to access them. The report of the Collegio dei Sindaci must be deposited 10 days prior to the Assembly.

## **TITOLO VI**

### **Art. 25 Responsibilities**

1. The governing bodies of the Federation do not meet the obligations assumed by the member associations and local bodies, which each meet only with their own funds and with their bodies Executives.
2. The president may sign obligation according to specific necessities such as loans with prior approval of the Board of Directors.

### **Art.26 Conflict of Interest and incompatibility**

1. The role of President, Vice President and other members of the Board of Directors are not compatible with executive roles, economic participations in organisms and companies or cooperatives or similar that have economical relations with facilities related to HHT.
2. The incompatibility is operative at the moment of elections.

## **TITOLO VII**

### **Art. 27 Final disposition**

1. For all that is not expressly stated in these statutes we must refer to law 266 del 1991, and to regional laws on the topic.