

Naevus Global: an international federation of congenital melanocytic nevus associations

Articles of Association

Article 1 - Name

The Association shall be named “NAEVUS GLOBAL”, hereinafter referred to as “NAEVUS GLOBAL” or “The Association.”

NAEVUS GLOBAL shall be governed by the French law of 01 July 1901 concerning non-profit associations, which shall regulate anything not foreseen under these Articles of Association.

Article 2 - Registered Office

The registered office of NAEVUS GLOBAL is the CITE DES ASSOCIATIONS, 93, la Canebière, 13001 MARSEILLE, France. The registered office of the Association may be transferred upon a decision of the General Assembly to any other place, decision which shall be published in the Annexes to the French Official Gazette according to French law.

Article 3 - Objectives

Mission

NAEVUS GLOBAL is an international federation of advocacy groups dedicated to improving the lives of people affected by congenital melanocytic nevi (CMN) and neurocutaneous melanocytosis (NCM) worldwide through the promotion of both biomedical research and improved access to information.

The association seeks:

- To promote recognition of the rare diseases, large/giant congenital melanocytic nevus (CMN) and neurocutaneous melanocytosis (NCM), among the general public, medical practitioners, and national and international health advocacy organizations
- To develop and share information related to CMN and NCM among the member associations in order to maintain consistency and quality of said information
- To promote worthwhile biomedical research held to international standards of scientific significance
- To promote centralized access to, and management of, data and biological samples useful to the biomedical research of CMN and NCM, including but not restricted to an international registry
- To identify and assist affected children in countries without structured medical care for CMN, in part by fostering new associations serving additional parts of the world

- For the above purposes, to maintain a multilingual website with up-to-date and vetted information on various topics relevant to people with CMN and NCM.

Article 4 – Membership

The signatory associations of NAEVUS GLOBAL are:

(Australia) Nevus Australia, represented by its president, Ms. Michelle Sibbons
 (France) Association Nævus Géant Congénital, represented on behalf of its president, Jean-Claude Babin, by its treasurer, Mr. Frédéric Barollet
 (France) Nævus 2000 France-Europe, represented by its president, Ms. Laurence Baert
 (Germany) Nävus-Netzwerk, represented on behalf of its president, Felix Pahnke, by Ms. Juliane Stubbe
 (Great Britain) Caring Matters Now, represented by its executive director, Ms. Jodi Whitehouse
 (Israel) Children of Light, represented by its president, Ms. Inbal Engler
 (Italy) Naevus Italia, represented by its Vice President, Ms. Stefania Tedoldi
 (The Netherlands) Nevus Netwerk Nederland, represented by its president, Mr. Stefan Wilms
 (Portugal) Associação Nevo Portugal, represented by its president, Ms. Rosa Fernandes
 (Spain) Asociación Española de Nevus Gigante (AsoNevus), represented by its president, Ms. Francisca Fernández
 (U.S.A.) Nevus Outreach, Inc., represented by its executive director, Mr. Mark Beckwith
 Chapter-at-large, represented by Ms. Biljana Zlatanovska Vladichevska, Macedonia

NAEVUS GLOBAL members fall into the categories of **active members** and the **chapter-at-large**, who are entitled to vote, **associate members**, and **honorary members**.

Active members

Active members are legally incorporated, non-profit patient advocacy associations including the signatories, representing the interests of people affected by CMN and NCM. Such associations represent people over at least a significant portion of, or all of, a country or international region.

Chapter-at-large

The chapter-at-large represents individuals around the globe who are not members of already existing associations and who have no national association. Individuals affected by CMN or NCM may become members of the chapter-at-large in order to benefit from a representative vote, but are also encouraged to affiliate with one of the incorporated associations or to found a new one in their own country. The delegate of the chapter-at-large is designated by vote at each General Assembly, and is allowed to vote alongside active members at the General Assembly.

Associate members

Associate members are other organizations, non-profit associations, or for-profit companies who accept the mission and objectives of NAEVUS GLOBAL. Associate members are not entitled to vote.

Honorary members

An honorary member is any person admitted as such by the General Assembly. Honorary members are not entitled to vote.

Applications for membership are sent to the Secretary, accompanied by the composition of the candidate member administration, its bylaws or statutes for future online publication, and a description of the number and type of people with CMN that it represents. The General Assembly has sole discretion in granting or refusing applications. It is not required to explain its decision. The Board of Directors may grant Associate membership in the interim at its own discretion. Admission as an Honorary member is decided under the same conditions at the General Assembly following a recommendation from at least three active members.

Article 5 - Meetings

Meetings utilizing electronic systems

The business, including voting, of the Executive Committee, or the Board of Directors, or the General Assembly of NAEVUS GLOBAL may be conducted using telephone, email, teleconferencing, videoconferencing or any other electronic means at its disposal, to the extent allowed by French law.

Assemblies

A General Assembly will be held at least annually in a location and a manner to be decided by the Board of Directors in accordance with the latest bylaws adopted by the General Assembly.

The General Assembly shall be fully empowered to achieve the objectives of NAEVUS GLOBAL. The General Assembly shall be composed of all active members. Associate and Honorary members may attend but may not vote.

For a list of votes to be conducted at each General Assembly, see Article 6, "Duties of the Secretary".

Each active member association may be represented by one individual whom it has appointed as a delegate. The chapter-at-large delegate is designated at the General Assembly. Each delegate may appoint a substitute who will have been declared to the Secretary at least one week before the Assembly; see Article 5, "Proxies".

The General Assembly shall decide the overall policy of NAEVUS GLOBAL. It shall appoint and dismiss officers, staff and other appointees, grant or deny applications for active membership, approve budgets and accounts, amend the Articles of Association, dissolve NAEVUS GLOBAL or expel members where necessary.

An Extraordinary Assembly may be convened at the discretion of the Board of Directors (Article 6, "Governance") for the delegation of signatures, hiring and dismissal of staff, disciplinary actions, amendments to the Articles of Association or dissolution of NAEVUS GLOBAL.

Proxies

When a member group is unable to send any delegate to a particular General Assembly, that member group shall have the option to appoint a proxy to vote on behalf of the absentee member group, in the elections to be held at that particular General Assembly.

- Voting by proxy shall be allowed only for elections held at a General Assembly and not for voting on motions at a General Assembly
- Only an active member, who attends a General Assembly, shall act as a proxy for another active member, who does not have an official delegate at the General Assembly.

At least thirty (30) days before the start of a General Assembly, the President shall nominate and authorize one of the delegates of an active member association as Proxy Officer for the General Assembly to receive and process all instructions for the appointment of proxies. In the absence of this Presidential appointment, the Secretary of the Board of Directors shall act as the Proxy Officer.

Instructions will consist of the delegate’s name, contact information, the active member association they represent, and the name of the active member association delegate they wish to appoint as their proxy. These instructions shall be submitted to the Proxy Officer no later than seven (7) days preceding the Assembly.

Having satisfied himself/herself that the instructions for proxy are genuine, the Proxy Officer shall confirm to the applying delegate that their instructions have been received.

The President or the Proxy Officer shall present a list of proxies for adoption by the General Assembly, showing delegates acting as proxies and the active member association(s) for which each proxy is authorized to vote.

Quora and Votes

A quorum of a General or an Extraordinary Assembly is defined as the presence of delegates or proxies from a majority of current active member associations. Voting may only take place if a quorum is present.

For votes to remove members or change these Articles of Association, the vote must be at least two-thirds of those present at the Assembly and proxies.

For votes to dissolve NAEVUS GLOBAL (see Article 8, “Dissolution”), the vote must be at least two-thirds of the current active membership, regardless of the number of current members present at a General or Extraordinary Assembly.

All other votes not specifically mentioned above will pass by a simple majority of those present at the Assembly and proxies.

In the case of a tied vote among the Board of Directors (Article 6, “Governance”), the President’s vote shall prevail. In the case of a tied vote among the General Assembly, the vote of the majority of the Executive Committee will prevail.

Article 6 - Governance

NAEVUS GLOBAL is governed by a Board of Directors (hereinafter called “the Board”), consisting of at least three and at most seven active member delegates as defined in Article 5. Board members are

elected to a two-year term by a simple majority at the relevant General Assembly. The initial Board of Directors shall be:

Frédéric Barollet
Inbal Engler
Heather Etchevers
Michelle Sibbons
Biljana Vladichevska – delegate from Chapter-at-large
Jodi Whitehouse
Stefan Wilms

An additional Board member is the Director of the International Registry, elected directly to this position by the General Assembly. This Director is in all other respects like the other Directors, and may be elected by the Board to the Executive Committee. The initial Director of the International Registry shall be Mark Beckwith.

The Board of Directors shall meet whenever it may be in NAEVUS GLOBAL's interests for it to do so. Resolutions of the Board of Directors shall only be valid if at least half of its members are present or represented. Each director may be represented by another director. Decisions shall be taken by simple majority of directors present or represented. Resolutions shall be recorded in a register signed by the President or by two officers and kept by the Secretary. Members may consult said register at any time.

Once elected to the Board, a delegate may serve their term to completion even if the association they represent subsequently does not remain an active member of NAEVUS GLOBAL.

Duties of the Board

The Board shall conduct the routine business of NAEVUS GLOBAL, including:

- Setting the date, time and place of the General Assembly
- Setting the date, time and place of any Extraordinary Assemblies
- Setting the membership dues
- Taking disciplinary measures (see Article 7)
- Making reports to the General Assembly as mentioned below
- Recommend changes in staff and appointees to General Assembly
- Electing associate members in the interim between General Assemblies
- Recommending honorary members to the General Assembly
- Recommending changes in these Articles to the General Assembly

This Board shall elect officers to an Executive Committee: a President, a Secretary, and a Treasurer.

Reports

The Board of Directors will prepare reports to be presented to the General Assembly. These reports will regard the activities of NAEVUS GLOBAL since the last General Assembly, or another suitable period. These reports will include, but are not limited to, financial and other activities conducted in fulfillment of the mission and goals of NAEVUS GLOBAL.

Executive Committee

The Executive Committee is made up of the President, the Secretary, and the Treasurer. Officers on the Executive Committee serve a term of 2 years.

The Executive Committee shall be fully empowered to govern and manage NAEVUS GLOBAL, save for those powers reserved for the General Assembly and Duties reserved for the entire Board. It may hire and dismiss staff upon approval by vote of the General Assembly or Extraordinary Assembly.

The Executive Committee may assist the Board of Directors in preparing reports for the General Assembly, in particular but not limited to presenting financial documents prepared by the Treasurer and assessed ahead of time for the approval of the General Assembly.

Duties of the Secretary

Notice of the venue and agenda of the General Assembly will be sent by the Secretary to all members within thirty (30) days of the General Assembly.

A vote must be conducted at each General Assembly on the following items:

- Admission of new members, if relevant
- Election of a new representative of the chapter-at-large, if relevant
- Acceptance of reports of actions conducted in fulfillment of the mission and goals of NAEVUS GLOBAL
- Acceptance of financial report
- Acceptance of provisional budget
- Establishment of dues for the coming year
- Other future proposed actions
- Election of members of the Board, if relevant
- Other matters present on the agenda.

Voting may only take place relative to business consigned to the agenda.

The minutes and resolutions of the General Assembly, signed by the Secretary and at least one other member of the Executive Committee, and any additional documents emanating from the General Assembly, shall be made available by the Secretary to all members within 30 days following the General Assembly and maintained for consultation by members, and transmission to the next Executive Committee.

Duties of the Treasurer

The Treasurer will prepare the accounts for the previous financial year (see "Finances", below), and the provisional budget for the upcoming financial year, for consideration by the Executive Committee in advance of the General Assembly.

The Treasurer is responsible for maintaining transparent accounting of the financial situation of NAEVUS GLOBAL, to be reported to any of its members (active, associate or honorary) upon request. The Treasurer is also responsible for collecting dues or reporting default to the Executive Committee in a timely manner.

Duties of the President

The President will represent NAEVUS GLOBAL in all matters internal and external and in particular, at the General Assembly as well as at relevant scientific meetings.

The President is responsible for transmitting a report of the outcome after each General or Extraordinary Assembly, to all members.

In collaboration with the Executive Committee, the President shall be responsible for the organization of the General Assembly.

Finances

The financial year shall close on 31 December.

The main sources of income are derived from membership dues allocated by the General Assembly and direct gifts to NAEVUS GLOBAL. All active members are required to pay membership fees. Membership fees will be established by the Board. Donations and gifts collected by NAEVUS GLOBAL must be used in accordance with the decisions of the General Assembly.

Term Limitations

No person shall be a member of the Board for more than three (3) consecutive terms. No person shall serve as an officer for more than three (3) consecutive terms. After a hiatus of one year, this limit is reset and a delegate may rejoin the Board.

Article 7 - Disciplinary measures

Definition

The Board of Directors of NAEVUS GLOBAL has the right to take disciplinary action in the following realms:

- Non-compliance with the Articles of Association or decisions of the latest General Assembly
- Actions incompatible with the mission of NAEVUS GLOBAL
- Default on payment of dues, unless the Executive Committee has issued an exemption due to extenuating circumstances

Preliminary sanctions

- Retrograde membership status – an active member becomes an associate member and loses their right to vote at the next General Assembly, and an associate member is not invited to renew their association with NAEVUS GLOBAL, until such time as they demonstrate their compliance with the article they have infringed
- Any other measure that the Board of Directors of NAEVUS GLOBAL deems appropriate to ensure the interests and position of the federation.

Procedure

- Before taking disciplinary action, the Board of Directors will issue the offending organization a final warning and a deadline by which the problem must be solved
- If a member does not resolve the problem, the Board of Directors shall notify the member of the preliminary sanction proposed
- Decisions for disciplinary cases proposed by the Board of Directors of NAEVUS GLOBAL will be ratified at the following General Assembly
- The member shall be notified immediately after the decision by the General Assembly by registered mail.
- If the problem has not been resolved by the following General or Extraordinary Assembly, the definitive sanction will be expulsion from NAEVUS GLOBAL.

Member resignation

A member may resign from NAEVUS GLOBAL at any time by written notice to the President. Membership dues for the financial year underway remain owed to the federation by formerly active members.

Expulsion

The Board of Directors of NAEVUS GLOBAL may expel a member of the Association if, in its unanimous opinion, the conduct of the member is detrimental to the interests or objectives of NAEVUS GLOBAL. The member organization must be heard or have been given a reasonable opportunity to be heard in person, in writing, or in any other documented manner.

Article 8 - Changes in statutes

Amendments to the Articles of Association

Unless otherwise required by law, any motion for an amendment to the Articles of Association shall be proposed by the Executive Committee or by at least one fifth of the active members of NAEVUS GLOBAL.

The Executive Committee shall inform the members of NAEVUS GLOBAL at least three months in advance of the date of the General Assembly due to vote on said motion.

Dissolution

The General Assembly may declare that NAEVUS GLOBAL is to be dissolved, provided the quorum and vote satisfy Article 5, "Quora and Votes".

The General Assembly shall appoint liquidators, establish their powers in accordance with the law and decide how to allocate the liquidation surplus, which shall be transferred to another association with similar objectives or distributed to all active members at the time of dissolution.

These statutes were voted unanimously by the representatives of signatory patient associations present at the meeting on 29 September 2013, in Marseille, France.