

# **Bylaws of the Association *NF Patients United*, Global Network of NF Support Groups**

## **Sec. 1: Name, Registered Office, and Scope of Activities**

- (1) The name of the Association shall be *NF Patients United, Global Network of Neurofibromatosis Support Groups* (registered in Austria under the name “NF Patients United, Globales Netzwerk von Neurofibromatose Selbsthilfegruppen”).
- (1) The Association shall have its registered office in Pfarrgasse 87, 1230 Vienna, Austria.
- (2) The Association shall carry out its activities internationally.

## **Sec. 2: Purpose**

The Association is not for profit and pursues exclusively and directly the purpose of promoting the well-being of people living with all types of Neurofibromatosis (NF).

## **Sec. 3: Means to Achieve the Purpose of the Association**

- (1) The purpose of the Association shall be achieved through the immaterial and material means listed under paras. 2 and 3.
- (2) The immaterial means shall be
  - a) promoting and stimulating collaboration and exchange between people with NF and organizations which support people with NF,
  - b) stimulating and promoting clinical, scientific, and pharmacological research in the field of NF with the clear aim of finding approaches to curing and developing therapies and palliative treatments,
  - c) encouraging people with NF to contribute to these research activities,
  - d) supporting services which are directly or indirectly to the benefit of people with NF (medical care, social assistance, advice and information, etc.),
  - e) coordinating scientific expertise and clinical know-how internationally,
  - f) collaborating with national and European governments and national and international organizations which defend the interests and needs of people with NF,
  - g) raising awareness for the wishes of people with NF, promoting a positive attitude of the broad public towards people with NF and strengthening the self-confidence of all those directly or indirectly affected by NF.

- i) lectures and meetings
- j) conferences and symposia (scientific conferences, meetings of patient groups, presentations, receptions, etc.)
- k) meetings of people with NF with family members, friends, donors, sponsors, and supporters
- l) discussion and training events
- m) publications (journals, books, newsletters, informational brochures and folders, and the like), information in electronic media (Internet, e-mail-newsletter, CD-ROMs, DVDs, pod casts, and the like)

(3) The required material means shall be raised through

- a) registration and membership fees
- b) subsidies
- c) donations
- d) fundraising campaigns and collections
- e) bequests
- f) sponsoring
- g) cooperation with companies and organizations
- h) national and international funding and funded projects
- i) licenses and patents
- j) proceeds from events or the Association's activities, donations, collections, bequests, and other benefits received

## **Sec. 4: Types of Membership**

- (2) The *NF Patients United* association is the network of national NF support groups in Europe. The members of the Association are either full, associate, or honorary members.
- (3) Full members shall be national NF support groups which are legally constituted as a not-for-profit organization under the legislation of their own countries and which fully participate in the activities of the Association.
- (4) Membership is – normally – not open to individuals. It shall, however, be possible to grant associate or honorary membership to persons or organizations. Associate members shall be members which promote the activities of the Association, but don't fulfill the criteria for full membership yet. Honorary members shall be persons or organizations that are awarded honorary membership for their special achievements for the Association.

## **Sec. 5: Becoming a Member**

- (1) Full membership shall be open to all national NF support groups which are legally constituted (registered) as a not-for-profit association under the legislation of their countries.

- (2) It shall be at the discretion of the full members to decide upon granting associate membership status to persons or organizations that want to support the *NF Patients United* Association.
- (3) The Executive Committee shall decide on the acceptance of full and associate members. Membership may be denied without reason. The General Assembly shall be entitled to appeal against the granting of a full membership.
- (4) Until the formation of the Association full members and associate members shall be preliminarily accepted by the founders of the Association or, in case the Executive Committee has already been appointed, by the Executive Committee. Their membership shall become final upon formation of the Association. If the Executive Committee is set up after formation of the Association, the (definite) acceptance of full and associate members shall be made by the founders of the Association up to that point in time.
- (5) Honorary membership shall be awarded by the General Assembly upon the application by the Executive Committee.

## **Sec. 6: Termination of Membership**

- (1) Membership shall be terminated upon death, with regard to legal persons and partnerships with legal capacity upon loss of their legal personality, upon voluntary resignation or expulsion.
- (2) Members may only resign with effect as of 31 December of each year upon at least three months' written notice to the Executive Committee. If notice is not given in a timely manner, the resignation shall become effective at the following date of termination. Whether notice was given in time shall be determined by the date of the postmark.
- (3) The Executive Committee may expel a member if, in spite of having received two written reminders and having been set a reasonable grace period, it has defaulted in paying the membership fees for more than six months. This shall not affect the member's obligation to pay the due membership fees.
- (4) The Executive Committee may also order the expulsion of a member from the Association for gross violation of other membership duties and for disreputable behaviour.
- (5) Upon an application by the Executive Committee, the General Assembly may resolve to withdraw honorary membership status for the reasons mentioned under para. 4.

## **Sec. 7: Rights and Obligations of Members**

- (1) All members are entitled to attend all events of the Association and to use all facilities of the Association. The voting right at the General Assembly and the right to elect and stand for election shall be reserved to the full members.
- (2) each member is entitled to demand a copy of these Bylaws from the Executive Committee

- (3) At least one tenth of the members may request the Executive Committee to convene a General Assembly.
- (4) In the course of each General Assembly the members shall be informed by the Executive Committee about the Association's activities and the management of the Association's finances. If at least one tenth of the members requests so and gives reasons for their request, the Executive Committee shall provide such information to the members concerned within four weeks.
- (5) The Executive Committee shall inform the members about the audited financial statements (accounts). If such information is provided in the course of the General Assembly, this shall be done by involving the Auditors.
- (6) The members are obliged to take their best efforts in order to promote the interests of the Association and to refrain from any actions which might affect the reputation and purpose of the Association. They shall observe the Bylaws of the Association and the resolutions adopted by the Association's bodies. The full and associate members are obliged to pay, in a timely manner, the registration fee and the membership fees in the amounts agreed upon by the General Assembly.

## **Sec. 8: Bodies of the Association**

The bodies of the Association shall be the General Assembly (secs. 9 and 10), the Executive Committee (secs. 11 to 13), the Auditors (sec. 14) and the Arbitration Board (sec. 15).

## **Sec. 9: General Assembly**

The General Assembly is the meeting of members within the meaning of the (Austrian) "Vereinsgesetz" (Act on Associations) of 2002. An ordinary meeting of the General Assembly shall be held once a year.

- (1) Extraordinary meetings of the General Assembly shall be held within two month upon
  - a) a resolution by the Executive Committee or by the ordinary General Assembly,
  - b) the written application by at least one tenth of the members,
  - c) the request of the Auditors (sec. 21 para. 5 1<sup>st</sup> sentence of the Act on Associations),
  - d) a resolution of the Auditors/an Auditor (sec. 21 para. 5 2<sup>nd</sup> sentence of the Act on Associations, sec. 11 para. 2 3<sup>rd</sup> sentence of these Bylaws),
  - e) the resolution of a court-appointed trustee (sec. 11 para. 3 last sentence of these Bylaws).
- (2) All members shall be invited both to the ordinary and the extraordinary meetings of the General Assembly at least two month in advance in writing, by fax, or by e-mail (to the fax number or e-mail address notified to the Association by the member). The invitation to the General Assembly shall state the agenda. The meetings shall be convened by the Executive Committee (para. 1 and para. 2 lit. a – c), by the Auditors/an Auditor (para. 2 lit. d) or by a court-appointed trustee (para. 2 lit. e).

- (4) Items may be put on the agenda if notified to the Executive Committee in writing, by fax or by e-mail at least one week prior to the date of the General Assembly.
- (5) Valid resolutions – except resolutions on motions to convene an extraordinary meeting of the General Assembly – may only be adopted on items on the agenda.
- (6) All members are entitled to attend the meetings of the General Assembly. Only full members shall have a voting right. Each member shall have one vote. If, however, there is more than one NF support group in a country, the country shall have one vote only. Transfers of voting rights to other members by means of written proxy shall be possible.
- (7) The General Assembly shall have a quorum regardless of the number of members present.
- (8) Normally, elections held and resolutions passed by the General Assembly shall require a single majority of the valid votes cast. Resolutions to amend the Bylaws of the Association or dissolve the Association shall require a qualified majority of two-thirds of the valid votes cast.
- (9) The General Assembly shall be chaired by the President, in his/her absence by the Vice President. If the Vice President is also prevented from attending, the most senior member of the Executive Committee who is present shall chair the meeting.

## **Sec. 10: Tasks of the General Assembly**

The following tasks shall be reserved to the General Assembly:

- a) resolutions on the budget;
- b) accepting and adopting the statement of accounts and the financial statements with the consultation of the Auditors;
- c) electing and expelling members of the Executive Committee and of Auditors;
- d) approving legal transactions between Auditors and the Association;
- e) official approval of the actions of the members of the Executive Committee;
- f) determining the amount of the registration fee and the membership fees for full and associate members;
- g) awarding and withdrawing honorary memberships;
- h) adopting resolutions on amendments of the Bylaws and the voluntary dissolution of the Association;
- i) deliberating and adopting resolutions on other issues on the agenda.

## **Sec. 11: Executive Committee**

- (1) The Executive Committee shall be composed of a maximum of nine members, namely the President and Vice President, the Secretary and Vice Secretary, the Treasurer and Vice Treasurer. At least three patient representatives must be a member of the Executive Committee. The members of the Executive Committee are nominated by the full members and elected by the General Assembly. No country may be represented in the Executive Committee by more than one member.

- (2) Whilst it is hoped that the Executive Committee will be representative of all of the regions where *NF Patients United* is represented, there shall be no requirement for this to be the case.
- (3) The Executive Committee shall be elected by the General Assembly. Upon resignation of an elected member the Executive Committee shall be entitled to co-opt another eligible member, who shall be approved at the following meeting of the General Assembly. If the Executive Committee would cease to exist for good or for an unforeseeable period of time without adding new members by means of co-opting, each Auditor shall be obliged to immediately convene an extraordinary meeting of the General Assembly for the purpose of electing a new Executive Committee. Should the Auditors also be incapable of action, each full member who becomes aware of the emergency situation shall without delay file an application with the competent court to have a trustee appointed, who shall convene an extraordinary meeting of the General Assembly without delay.
- (4) The term of office of the Executive Committee shall be two years; members may be re-elected once, provided that a nomination by a full member (i.e. a national NF support group) is made. Each function on the Executive Committee shall be exercised by the respective members in person.
- (5) The Executive Committee is convened by the President, in his/her absence by the Vice President, either in writing or verbally. If the Vice President is also prevented from attending for an unforeseeable period of time, any other member of the Executive Committee shall be entitled to convene a meeting of the Executive Committee.
- (6) The Executive Committee shall have a quorum if all members have been invited and at least half of them are present.
- (7) The Executive Committee shall pass its resolutions by simple majority of the votes cast; in case of a tie the President shall have the casting vote.
- (8) The meetings of the Executive Committee shall be chaired by the President, in his/her absence by the Vice President. If the Vice President is also prevented from attending, the most senior member of the Executive Committee or a member appointed by the majority of all other members of the Executive Committee shall chair the meeting of the Executive Committee.
- (9) Apart from death and expiry of the term of office (para. 4), the office of a member of the Executive Committee shall also be terminated by means of removal from office (para. 10) and resignation (para. 11).
- (10) The General Assembly may at any time remove the entire Executive Committee or individual members of the Executive Committee. The removal shall become effective upon appointment of a new Executive Committee or a new member of the Executive Committee.
- (11) The members of the Executive Committee may at any time declare their resignation in writing. The resignation shall be addressed to the Executive Committee or, in case the entire Executive Committee is resigning, to the General Assembly. After a resignation, the resigned members shall be replaced as soon as possible, either by means of co-opting a successor or in the course of the following election.

## **Sec. 12: Tasks of the Executive Committee**

The Executive Committee shall be responsible for managing the Association. It is the management body within the meaning of the Act on Associations of 2002. It shall be responsible for all tasks which are not allocated to another body of the Association by virtue of these Bylaws. The Executive Committee shall meet at least once a year. Its responsibilities shall include, without limitation, the following matters:

- (1) establishing an accounting system which meets the requirement of the Association, the minimum requirements being the current recording of receipts and expenditures and keeping an inventory of assets;
- (2) preparing the budget, the statement of accounts, and the financial statements;
- (3) preparing and convening the General Assembly in the cases described under sec. 9 para. 1 and para. 2 lit. a – c of these Bylaws;
- (4) informing the members of the Association about the activities of the Association, the administration of its assets, and the audited financial statements;
- (5) managing the Association's assets;
- (6) accepting and expelling full, associate, and supporting members of the Association;
- (7) hiring and dismissing employees of the Association.

The Executive Committee shall maintain a bank account in the name of "NF Patients United" for managing all financial transactions. The account is only to be used for *NF Patients United* business. Any payment from that account must be authorized by at least two signatories, of whom one shall be the Treasurer. In the case of payments exceeding EUR 10,000.00, three signatories shall be required, of whom one shall be the Treasurer.

## **Sec. 13: Special Duties of Individual Members of the Executive Committee**

- (1) The President shall manage the current transactions of the Association. The Secretary shall assist the President in managing the affairs of the Association.
- (2) The President shall represent the Association to the outside world. Written documents of the Association shall be signed by the President and by the Secretary in order to be effective, if financial matters are concerned (dispositions regarding assets) the signature of the President and of the Treasurer shall be required. Legal transactions between members of the Executive Committee and the Association shall be subject to the approval of another member of the Executive Committee.
- (3) Power-of-attorney to represent the Association to the outside world and/or to sign on behalf of the Association may be granted exclusively by the members of the Executive Committee listed under para. 2.
- (4) In the case of imminent danger, the President is entitled to independently give instructions, even in matters falling within the scope of responsibility of the General Assembly or of the Executive Committee, in his/her own responsibility; internally these instructions shall, however, require the subsequent approval of the competent body of the Association.
- (5) The President shall chair the meetings of the General Assembly and of the Executive Committee.

- (6) The Secretary shall be responsible for the minutes of the meetings of the General Assembly and the Executive Committee.
- (7) The Treasurer shall be responsible for the proper management of the finances of the Association.
- (8) If they are prevented from exercising their duties, the President, the Secretary, or the Treasurer shall be represented by their deputies.

## **Sec. 14: Auditors**

- (1) The General Assembly shall elect two Auditors for a period of three years. The auditors may be re-elected. The Auditors must not be members of any body – except for the General Assembly – whose activities are the subject matter of the audit.
- (2) The Auditors shall be responsible for auditing the current transactions and the management of finances of the Association with a view to proper accounting and the use of the funds in accordance with these Bylaws. The Executive Committee shall submit the required documents to the Auditors and provide them with the required information. The Auditors shall report to the Executive Committee on the results of the audit.
- (3) Legal transactions between the Auditors and the Association shall be subject to the approval of the General Assembly. The provisions of sec. 11 paras. 9 to 11 shall apply analogously to the Auditors.

## **Sec. 15: Arbitration Board**

- (1) The Association's internal Arbitration Board shall be responsible for settling all disputes arising in connection with the Association. It is the arbitrating body ("*Schlichtungseinrichtung*") within the meaning of the Act on Associations of 2002 and not an arbitration tribunal pursuant to secs. 577 et. seq. of the (Austrian) "*Zivilprozessordnung*" (Code of Civil Procedure).
- (2) The Arbitration Board shall be composed of three full members of the Association. To set up the Arbitration Board, one party in dispute shall nominate in writing one member to the Executive Committee as an arbitrator. At the request of the Executive Committee, which shall be made within seven days, the other party shall then nominate another member of the Arbitration Board within 14 days. After having informed the Executive Committee accordingly within seven days, the nominated arbitrators shall within 14 days elect a third full member the Chairperson of the Arbitration Board. In case of a tie, the Chairperson shall be chosen from among the nominated members by lot. The members of the Arbitration Board must not be members of any body – except for the General Assembly – whose activities form the subject matter of the dispute.
- (3) The Arbitration Board shall come to its decision after having heard both parties in the presence of all its members by simple majority of the votes. It shall decide to the best of its knowledge and belief. Internally, its decisions shall be final for the Association.



## **Sec. 16: Voluntary Dissolution of the Association**

- (1) The voluntary dissolution of the Association may only be resolved upon in a meeting of the General Assembly convened for such purpose and shall require a two-thirds majority of the valid votes cast.
- (2) The same meeting of the General Assembly shall also decide on the liquidation of the Association's assets, provided that such assets exist. In particular, it shall appoint a liquidator and pass a resolution on to whom the liquidator shall transfer the assets remaining after deduction of all liabilities.
- (3) The same meeting of the General Assembly may decide that the capital contributions paid in and the fair market values of the contributions in kind, which shall be determined as of the date of making the contribution, shall be paid back to the members.
- (4) In the case of voluntary dissolution, dissolution of the Association by order of the competent public authority, or loss of the Association's tax-privileged purpose any remaining assets of the Association must inure to the benefit of not-for-profit entities within the meaning of sec. 34 of the (Austrian) BAO (Federal Fiscal Code) which shall use such assets exclusively for purposes laid down in sec. 4a (3) of the (Austrian) EStG (Income Tax Act) of 1988. If possible, the assets should inure to the benefit of the members who fulfill these criteria. If this is not possible, the General Assembly shall decide which not-for-profit entity within the meaning of secs. 34 et seq. of the Federal Fiscal Code the assets should be transferred to for the exclusive use for purposes laid down in sec. 4a (3) of the Income Tax Act.
- (5) The last Supervisory Board of the Association shall notify the competent security directorate ("*Sicherheitsdirektion*") about the dissolution of the Association in writing within four weeks after adoption of the resolution.

