

**REVISED AND REWORDED BYLAWS OF THE
INTERNATIONAL F.O.P. ASSOCIATION INC.**

ARTICLE 1

NAME

The name of the Association is International F.O.P. Association Inc. (the "Association"). It is intended that the Association shall have the status of a corporation which is exempt from federal income taxation under Section 501(a) of the Internal Revenue Code of 1986, as amended (hereinafter referred to as the "Code"), as an organization described in Section 501(c)(3) of the Code.

ARTICLE 2

OFFICES

Section 2.1 Corporate Office. The principal office of the Association shall be located at 101 Sunnyside Road, Suite 208, Casselberry, Florida, 32707, USA. The Association may have such other offices, either within or without the State of Florida, as the Board of Directors may designate or as the affairs of the Association may require from time to time.

Section 2.2 Registered Office. The registered office of the Association required to be maintained in the State of Florida by the Florida Not For Profit Corporation Act, as amended from time to time (hereinafter referred to as the "Act") may, but need not, be identical with the principal office in the State of Florida; and the address of the registered office may be changed from time to time by the Board of Directors.

ARTICLE 3

PURPOSE, USE, AND ADMINISTRATION OF FUNDS

Section 3.1 Purpose. The Association is organized exclusively for charitable and educational purposes within the meaning of Section 501(c)(3) of the Code (hereinafter referred to as "Charitable Purposes"), including the receipt and acceptance of property, whether real, personal or mixed, by gift or bequest from any person or entity; the retention, administration, investment and distribution of such property in accordance with these By-Laws. The specific purposes and objectives of the Association shall include but not be limited to the following:

- 3.1.1 To promote and fund research into Fibrodysplasia Ossificans Progressiva ("F.O.P.");
- 3.1.2 To develop and disseminate information to educate the public concerning F.O.P.;
- 3.1.3 To develop a support network for families affected by F.O.P.;

- 3.1.4 To publish a newsletter and website for families and others dealing with the challenges of F.O.P., as well as other interested persons;
- 3.1.5 To solicit and receive gifts, bequests, donations, contributions, and conveyances of real estate, stocks, securities, commodities, monies and any and all real and personal property, the net income and principal of which shall be used exclusively in furtherance of the charitable and educational purposes set forth in the preceding paragraphs.

Section 3.2 Use of Funds. In making distributions to effectuate the Charitable Purposes of the Association, as delineated in Section 3.1 above, the Board of Directors shall have the authority to make distributions of both income and principal in such proportions and amounts as the Board of Directors, in its discretion, determines advisable, provided that all such distributions are for Charitable Purposes and are consistent with all applicable federal tax laws and regulations, as herein provided. The primary consideration of the Board of Directors shall be income distributions, but the Board of Directors shall also be authorized to make distributions of principal from time to time as the Board of Directors, in its discretion, shall determine. The Association is not formed for financial or pecuniary gain; and no part of the assets, income, or profits of the Association shall be distributable to, or inure to, the benefit of its directors or officers or any other private person, except as provided in Section 5.10, Section 6.11 and Article 12 as reimbursement for expenses and payment of reasonable stipends of officers, and except to make payments and distributions in furtherance of the charitable and educational purposes of the Association, as set forth in the Charter and Section 3.1 above. No substantial part of the activities of the Association shall be the carrying on of propaganda, or otherwise attempting to influence legislation; and no part of the activities of the Association shall be the participation in, or intervention in (including the publishing or distributing of statements), any political campaign on behalf of (or in opposition to) any candidate for public office.

Section 3.3 Administration of Funds. In the event the Association is a private foundation within the meaning of Section 509 of the Code for a taxable year, the Association (a) shall distribute its income for such tax year in such manner so that it will not become subject to the tax or undistributed income imposed by Section 4942 of the Code, or corresponding provisions of any later federal tax laws; (b) shall not engage in any act of self-dealing, as defined in Section 4941(d) of the Code, or corresponding provisions of any later federal tax laws; (c) shall not retain any excess business holdings, as defined in Section 4943(c) of the Code, or corresponding provisions of any later federal tax laws; (d) shall not make any investments in a manner that would incur tax liability under Section 4944 of the Code, or corresponding provisions of any later federal tax laws; and (e) shall not make any taxable expenditures, as defined in Section 4945(d) of the Code, or corresponding provisions of any later federal tax laws. In order fully to effectuate the provisions of this Section, the Association shall adopt such procedures, and shall otherwise adhere to such administrative requirements as may from time to time be necessary, in order fully to comply with all applicable federal tax laws and regulations.

Section 3.4 Termination of Association. The Board of Directors shall have the authority to terminate the Association at any time that, by a unanimous vote, it deems such termination

appropriate or advisable. In such event, after paying, or making provision for the payment of, all liabilities of the Association then outstanding and unpaid, the Board of Directors shall distribute the assets of the Association exclusively for its charitable and educational purposes. Any assets not so disposed of by the Board of Directors shall be disposed of by a court having equity jurisdiction in the county in which the principal office of the Association is then located, with the distribution of assets to be made for such charitable and educational purposes or to such charitable organizations as such court shall determine.

ARTICLE 4

MEMBERS

Section 4.1 Eligibility for Membership. Membership is open to anyone with an interest in the Association and its purposes.

Section 4.2 Manner of Application and Approval. All persons who are eligible for membership and pay dues to the Association (subject to the qualifications set forth below) shall be an individual member and have the benefits, privileges, and obligations provided in the By-laws and Policies of the Association. All persons eligible for membership shall make application to the Association in such manner and on such forms as shall be prescribed by the Executive Committee.

Section 4.3 Dues; Term; Other Conditions. Members shall pay such dues and in such manner as prescribed by the Board of Directors. Persons who have FOP and their parents or guardians may request Sponsorship of their dues by notifying the Association of their desire to have regular membership status and of their inability to pay the dues. The privilege of Sponsorship continues for the parents or guardian of a deceased person with FOP for as long as the sponsorship is requested. Membership in the Association will be for such term and subject to such conditions, including voting rights, as established by the Board from time to time.

Section 4.4 Annual Membership Meeting. The Association shall hold an annual meeting of its membership by electronic mail and/or hardcopy mail in the fall of each year, or at such other time and date as shall be determined by the Board of Directors. The purpose of the annual meeting shall be to elect directors and to transact such other business as may properly be brought before the meeting. For voting purposes, a majority of votes submitted shall constitute a decision by the full membership.

Section 4.5 Termination of membership. Membership may be terminated at any time, with cause, by affirmative vote of two-thirds of the Board of Directors, after providing notice and the opportunity of being heard to the member in whatever manner is prescribed by the Executive Committee.

ARTICLE 5

BOARD OF DIRECTORS

Section 5.1 General Powers. The business and affairs of the Association shall be supervised by its Board of Directors, which shall exercise in the name of and on behalf of the Association all of the rights and privileges legally exercisable by the Association as a corporate

entity, except as may otherwise be provided by law, or these By-Laws. The Board shall be responsible for overall policy and direction of the Association.

Section 5.2 Number, Tenure, and Qualifications. There shall be a minimum of nine (9) and a maximum of fifteen (15) directors of the Association, who shall be nominated by the Board of Directors and elected by the Membership for terms commencing January 1 of the succeeding year. The amount and type of work to be done should drive the number of board member nominees that the Board Development and Nominating Committees is asked to provide. The number of directors may be changed by vote of a majority of the entire Board. No decrease in member number may shorten the term of any incumbent director(s); therefore, the decrease shall be implemented at regular election time. Each elected director shall serve a term of two (2) years, with terms staggered in correlation to the way in which such directors were elected. In accordance with the method of electing new board members to fill a vacancy in Section 5.9 herein, any directorship to be filled by reason of an increase in the number of directors may be filled by election by the Board of Directors for a term of office continuing only until the next election of directors. Each director shall hold office until his or her term shall have expired and his or her successor shall have been elected and qualified, or until his or her earlier resignation, removal from office, or death. A retiring director may succeed himself or herself. Jeannie Peeper, the Founder of the International F.O.P. Association, during her lifetime, or until such time as she is no longer willing or able to serve, shall fill one of the positions as Director if she so desires. Directors shall be natural persons who have attained the age of eighteen years of age, but need not be residents of the State of Florida. Only one member of any household can be a voting member of the board at a time. Consistent with the original goal of the Association of bringing together persons with F.O.P., the Board of Directors shall, if at all possible, include at least two persons with F.O.P., even if one is in an advisory capacity.

Section 5.3 Annual Meeting. The Annual Meeting of the Board of Directors shall be held within or without the State of Florida, in whatever manner is decided by the Chairperson of the Board, in December of each year, or at such other time and date as shall be determined by the Board of Directors. It shall be held in conjunction with the annual meeting of the Association, or as shortly thereafter as possible. This meeting may be held by means of telephone conference or similar communication equipment. The purpose of the annual meeting shall be to elect officers and transact such other business as may properly be brought before the meeting.

Section 5.4 In Person Board of Directors Meeting and other Special Meetings. In order to facilitate the smooth functioning of the dispersed Board of Directors, the Board of Directors shall hold at least one In Person Board of Directors meeting each year at a time, date and location to be decided by the Board. The purpose of these In Person Board of Directors meetings is to review the overall status of the Association, hear reports from committee chairpersons and relevant specialists (e.g. Operations Manager, Accountant, scientific advisors), design plans for the future, and transact such other business as may properly be brought before the meeting. Other Special Meetings of the Board of Directors may be called by the Chairperson of the Board, or at the request of the Secretary or any two (2) directors. The Chairperson shall fix the time and place of any such Special Meeting, which may be held by means of telephone conference, electronic mail, or similar communication equipment.

Section 5.5 Notices. Notice of any special meeting shall be given at least five (5) business days prior thereto. The attendance of a director at a meeting shall constitute a waiver of notice of such meeting, except where a director attends a meeting for the express purpose of objecting to the transaction of any business because the meeting was not lawfully called or convened. The business to be transacted at, or the purpose of, any special meeting of the Board of Directors must be specified in the notice of such meeting.

Section 5.6 Quorum. A majority of the total number of directors in office shall constitute a quorum for the transaction of business at any meeting of the Board of Directors.

Section 5.7 Participation in Meeting. Each director, other than an advisory member, shall be entitled to one (1) vote upon any matter properly submitted for a vote to the Board of Directors. The affirmative vote of a majority of the directors present at a meeting at which a quorum is present shall be the act of the Board of Directors, except as may otherwise be specifically provided by law, or by these By-Laws. Members of the Board of Directors absent from any meeting shall be permitted to vote at such meeting by written proxies in such manner and on such forms as shall be prescribed by the Executive Committee. The members of the Board of Directors, or any committee designated by the Board of Directors, may participate in a meeting of the Board of Directors, or of such committee, by means of conference telephone, electronic mail, or similar communications equipment by means of which all persons participating in the meeting can hear one another or read the comments of each person attending; and the participation in a meeting pursuant to this provision shall constitute presence in person at such meeting. The directors shall be promptly furnished a copy of the minutes of the meetings of the Board of Directors. In order to insure a vibrant and participatory board, two missed meetings of any type (in person or scheduled quarterly) in one year by a director is an "automatic resignation" from his or her two year term, in accordance with Section 5.13 of these Bylaws.

Section 5.8 Action Without a Meeting. Any action required or permitted to be taken at a meeting by the Board of Directors, or by any committee thereof, may be taken without a meeting if all members of the Board of Directors or committee, as the case may be, consent in writing to taking such action without a meeting. If all members entitled to vote on the action shall consent in writing to taking such action without a meeting, the affirmative vote of the number of votes that would be necessary to authorize or take such action at a meeting shall be the act of the Board of Directors. The action must be evidenced by one (1) or more written consents describing the action taken, signed in one (1) or more counterparts by each member entitled to vote on the action, indicating each signing member's vote or abstention on the action taken. All such written consents and actions shall be filed with the minutes of the proceedings of the Board of Directors or committee. A consent signed under this Section shall have the same force and effect as a meeting vote of the Board of Directors, or any committee thereof, and may be described as such in any document.

Section 5.9 Vacancies. Any vacancy occurring in the Board of Directors, including vacancies created by the removal of directors without cause or for cause, may be filled by the affirmative vote of a majority of the Directors. A director elected to fill a vacancy shall serve for the unexpired term of his or her predecessor in office, or, if there is no predecessor, until the next election of directors. If a vacancy is not filled within ninety (90) days of the event which resulted

in there being fewer directors than the minimum required by the By-Laws, any director may apply to a court having equity jurisdiction in the county in which the Association has its principal office to have such court appoint a sufficient number of directors so that the Association will have the minimum number of directors required by its By-Laws. Any directorship to be filled by reason of an increase in the number of directors may be filled by election by the Board of Directors for a term of office continuing only until the next election of directors (as per Section 5.2).

Section 5.10 Compensation and Reimbursement of Expenses. Each director shall serve in such capacity without compensation for services rendered to the Association. However, each director may be paid his or her reasonable expenses incurred by the director directly related to the affairs of the Association upon prior approval by the Board of Directors and proper substantiation of such expenses.

Section 5.11 No Presumption of Assent. A director of the Association who is present at a meeting of the Board of Directors at which action on any Association matter is taken, but who does not comment or otherwise participate in a timely manner as set forth by the relevant Policies & Procedures of the Association, shall not be presumed to have agreed with the action so taken. Directors are encouraged to exchange ideas and observations before voting, but if a Director submits a vote without comment, it is still an acceptable vote. If that Director applies to serve or is considered for another term, however, the Board Development and Nominating Committee may consider the failure to adequately comment as a negative sign as it evaluates the incumbent. A director of the Association who is present at a meeting of the Board of Directors at which action on any Association matter is taken will be presumed to have missed that meeting if no timely vote is received by the Secretary.

Section 5.12 Removal. Any or all of the directors may be removed for cause or without cause by vote of two-thirds (2/3) of the total number of the voting directors. Removal of a director shall constitute removal as an officer of the Association and as a member of all committees of the Board of Directors.

Section 5.13 Resignation. A director may resign his or her membership at any time by tendering his or her resignation in writing to the Chairperson or, in the case of the resignation of the Chairperson, to the Secretary. A resignation shall become effective upon the date specified in such notice or, if no date is specified, upon receipt of the resignation by the Association at its principal place of business. Furthermore, in order to insure a vibrant and participatory board in accordance with Section 5.7 of these Bylaws, two missed meetings (in person, or scheduled quarterly) in one year by a director is an “automatic resignation” from his or her two year term. A vote by written proxy, as per Bylaw 5.7, shall not constitute attendance for the purposes of this bylaw. Attendance of a director by communication equipment as per Bylaw 5.7 for less than the full time scheduled for a meeting shall not constitute attendance for the purposes of this bylaw unless otherwise approved by the Board Chairperson.

ARTICLE 6

OFFICERS

Section 6.1 Number. There shall be a President, Chairperson of the Board, Vice-Chairperson, Secretary, and Treasurer of the Association, each of whom shall be elected in accordance with the provisions of this Article. No one individual may hold more than one office on a permanent basis, although an individual may do so temporarily (except the offices of Chairperson and Secretary together) while the Board takes the actions necessary to properly fill said officer positions.

Section 6.2 Election and Term of Office. The officers of the Association shall be elected by the Board of Directors at its annual meeting. If the election of the officers shall not be held at such meeting, such election shall be held as soon thereafter as may be convenient. Each officer shall hold office for a term of two (2) years expiring immediately following the annual meeting at which he or she was elected and until his or her successor shall have been duly elected and qualified, or until his or her earlier death, resignation, or removal from office in the manner hereinafter provided. If a board member is elected to an office, the term for which extends beyond his/her term as a board member, that member's board term is extended to match the term of office to which he/she was elected, excepting that if the officer position being filled is that of chairperson, the board member must be re-elected to the board for a new two-year term prior to standing for election as chairperson. If the terms of office of the chairperson and two or more officers can be foreseen to expire at the same time, the Board may at its option reduce or extend the term of office of the chairperson and any incumbent officer or officers by one year. A retiring officer may succeed himself or herself in his or her office.

Section 6.3 President. Jeannie Peeper, the Founder of the International F.O.P. Association, shall be its President during her lifetime, or until such time as she is no longer willing or able to serve. The President will perform ceremonial functions and act as spokesperson for the organization, if she sees fit to do so. When the time comes that Jeannie Peeper is no longer serving as President, the Board will then assess the needs of the organization and make whatever changes are required to maximize the continuing functioning of the Association which may include choosing another President to act as spokesperson and role model. In keeping with the original goal of the Association of bringing together persons with F.O.P., such a spokesperson and role model should be a person with F.O.P., unless circumstances require otherwise.

Section 6.4 Chairperson of the Board. The Chairperson of the Board shall be the principal executive officer of the Association, providing direction and oversight, and working closely with the Executive Committee, the Board of Directors, Operations Manager and President to create and implement the goals and action plans of the Association. S/he shall have the power to call special meetings and to constitute special committees and make appointments to standing committees. He or she shall, when present, preside at all meetings of the Board of Directors and Executive Committee, and shall, in general, perform all of the duties as may from time to time be prescribed by the Board of Directors. If any vote of the Board of Directors results in a tie, the Chairperson shall abstain in order to keep the vote at an odd number sufficient to result in a valid decision. The Chairperson may sign, with the Secretary or any other proper officer thereunto authorized by the Board of Directors, deeds, mortgages, bonds, contracts, or other instruments which the Board of Directors has authorized to be executed except in cases where the signing and execution thereof shall be expressly delegated by the Board of Directors of these By-laws to some other office or agent of the Association, or shall be required by law to be otherwise signed or executed.

Section 6.5 Vice-Chairperson. The Vice-Chairperson shall be prepared to step into the Chairperson position if and when it becomes necessary, exercising the functions of the Chairperson during the absence or disability of the Chairperson, or in the event of his or her death, inability, or refusal to act. Pending election, if necessary, of a successor in accordance with the method of electing board members to fill a vacancy in Section 6.9 below, the Vice-Chairperson shall have all the powers of, and be subject to all the restrictions upon, the Chairperson. The Vice-Chairperson shall assist the Chairperson as requested, and perform such other duties as may from time to time be assigned to him or her by the Chairperson and/or by the Board of Directors.

Section 6.6 Secretary. The Secretary shall be responsible for keeping records of Board actions, including overseeing the taking of minutes at all Board of Directors and Executive Committee meetings, and perform such other duties as may from time to time be assigned to him or her by the Chairperson and/or by the Board of Directors.

Section 6.7 Treasurer. The Treasurer shall have charge of and be responsible for all funds and securities of the Association, for the following: advising the Chairperson and the Board of Directors on all financial matters; serving as a voting member of the Finance and Audit Committee, and for such other duties as may from time to time be assigned to him or her by the Chairperson and/or by the Board of Directors.

Section 6.8 Removal. Any member of the Board of Directors removed from office pursuant to Section 5.13 shall be automatically removed as an officer. The Board of Directors may by a two-thirds (2/3) vote remove any officer when, in its judgment, the best interests of the Association will be served thereby.

Section 6.9 Vacancies. A vacancy in any office, because of death, resignation, removal, disqualification, or otherwise, may be filled by the affirmative vote of a majority of the Board of Directors for the unexpired portion of the term. In accordance with Section 6.2, the term of a board member appointed to fill a vacancy shall be extended to enable the Board member to serve for the unexpired portion of the term of office vacated, excepting that if the vacancy being filled is that of chairperson, the appointee must be re-elected to the board for a new two-year term at the next annual meeting of the membership before standing for election for a full two-year term as chairperson.

Section 6.10 Resignation. An officer may resign his or her office at any time by tendering his or her resignation in writing to the Chairperson or, in the case of the resignation of the Chairperson, to the Secretary. A resignation shall become effective upon the date specified in such notice, or, if no date is specified, upon receipt of the resignation by the Association at its principal place of business.

Section 6.11 Salaries and Expenses. As a volunteer organization, the officers of the Association shall serve without compensation. However, the Board may, by specific resolution, authorize the payment of a reasonable stipend on a quarterly or monthly basis and pursuant to such terms and conditions as the Board shall establish for extraordinary services rendered on behalf of the Association by an officer. The Board shall establish guidelines for the payment of said stipend, which shall be reviewed from time to time as circumstances warrant. Reasonable expenses

incurred by all of the officers in the course of coordinating the affairs of the Association shall be reimbursed by the Association upon proper substantiation.

ARTICLE 7

OPERATIONS MANAGER

Section 7.1 General Information: An Operations Manager of the Association shall be hired by the Chairperson of the Board in such manner as shall be prescribed by the Executive Committee, with the final selection being approved by the Board of Directors. The Operations Manager will be the Chief Operating Officer of the Association and shall perform such other duties as may from time to time be assigned to him or her by the Chairperson, Vice-Chairperson, Executive Committee, and/or by the Board of Directors. The Operations Manager shall be an employee of the Association, and the Chairperson of the Board may terminate the employment of the Operations Manager, with the approval of the Board of Directors.

Section 7.2 Responsibilities:

The Operations Manager is responsible for working closely with the Chairperson and the Executive Committee, and for the following: providing direction for and management of daily operations of the organization, pursuing the organization's goals and policies; reporting on the progress of the organization; answering questions of the board members; providing relevant input to the Chairperson and Executive Committee for meetings; participating without a vote in Executive Committee and Board of Directors meetings, carrying out the duties in the Operations Manager's job description and for such other duties as may from time to time be assigned him or her by the Chairperson, Vice Chairperson, Executive Committee or Board of Directors.

ARTICLE 8

EXECUTIVE COMMITTEE AND OTHER COMMITTEES

Section 8.1 Executive Committee. The Board of Directors, by resolution adopted by a majority of its voting members, shall designate the Chairperson, and two (2) or more of its other members to constitute an Executive Committee. Only one member of a family, extended or otherwise, may serve on the Executive Committee at a given time. A Member-at-Large may be appointed to serve as a member of the Executive Committee for one year to assist in advancing the goals and objectives of the Executive Committee and the Association. In no event shall the Executive Committee constitute a majority of the Board. If for any reason or cause the Executive Committee becomes a majority of the Board, where an immediate increase in Board members to achieve Board majority is not reasonably foreseen, the Chairperson shall cause one or more members of the EC to resign such that the EC no longer constitutes a majority of the Board. The Operations Manager shall participate in the Executive Committee meetings, but without a vote. Each member of the Executive Committee shall hold office until the next annual meeting of the Board of Directors following his or her designation and until his or her successor has been appointed and qualified. The designation of the Executive Committee and the delegation of authority thereto shall not operate to relieve the Board of Directors, or any member thereof, of any responsibility imposed by law. The Executive Committee, when the Board of Directors is not in

session, shall have and may exercise all the authority of the Board of Directors except to the extent, if any, that such authority shall be limited by the resolution appointing the Executive Committee or by these By-Laws. All action taken by the Executive Committee shall be subject to ratification by the Board of Directors.

However, the Executive Committee shall not have the authority of the Board of Directors with respect to filling any vacancy on the Board of Directors; amending or repealing any resolution of the Board of Directors which by its express terms is not so amendable or repealable; adopting a plan of merger or consolidation; selling, leasing, or otherwise disposing of all or substantially all the property and assets of the Association other than in the usual and regular course of its business; or voluntarily dissolving the Association or revoking a voluntary dissolution.

Section 8.2 Committees of the Board. All committees, other than the Executive Committee, shall be under the control and serve at the pleasure of the Board of Directors, shall have charge of such duties as may be assigned to them by the Board or these By-Laws, shall maintain a permanent record of their actions and proceedings, and shall regularly submit a report of their actions to the Board, which shall ratify the actions of each committee. The Chairperson, or his or her designee, shall serve on each committee as an ex-officio member.

Section 8.3 General Provisions for Standing Committees. Unless otherwise provided herein and subject to the approval of the Board of Directors, the Chairperson of the Board shall appoint the chairpersons and the members of all standing committees, except the Board Development and Nominating Committee, at each annual meeting of the Board, or as soon as practicable thereafter. Board Development and Nominating Committee members shall be selected by the Executive Committee. The chairpersons and the members of each standing committee shall be appointed from among the membership of the Association and/or the Board of Directors to hold office for a term of one (1) year, commencing January 1 following the meeting at which they are appointed and ending the following December 31, at which their successors are appointed and qualified, or until their earlier death, resignation or removal.

- 8.3.1 A member of a standing committee may resign at any time by giving written notice both to the Chairperson of the Board and the chairperson of the committee from which the member is resigning;
- 8.3.2 The Board may remove a member of a standing committee when, in its judgment, the best interests of the Association will be served by such removal;
- 8.3.3 The Chairperson shall fill all vacancies in standing committees, subject to the approval of the Board;
- 8.3.4 Meetings of standing committees may be called by their respective chairpersons or by the Chairperson. Each committee shall meet as often as is necessary to perform its functions;

- 8.3.5 Each standing committee may adopt rules for its own governance, provided such rules are not inconsistent with the law, or these By-Laws;
- 8.3.6 A majority of the voting members of a committee shall constitute a quorum for the transaction of business at any committee meeting. The act of a majority of the members of a standing committee present at a meeting at which a quorum is present shall be the act of the committee. Unless otherwise provided, a chair of a standing committee shall be entitled to vote on any question before the committee;
- 8.3.7 Each standing committee may invite additional individuals with expertise or familiarity in a pertinent area to meet with and assist the committee. Such individuals shall not vote or be counted in determining the existence of a quorum and may be excluded from any executive session of the committee.

Section 8.4 Standing Committees. The Board of Directors shall maintain the following standing committees, and such additional standing committees as it may determine from time to time to be necessary or desirable for its proper functioning:

(a) Fund Development Committee. With input from the Executive Committee, the Fund Development Committee shall work with the Operations Manager to ensure the long term viability of the organization and assist the Operations Manager in securing sufficient funding to ensure that operating expenses, existing programs, and new projects are adequately funded. Such collaboration shall include, but not be limited to, identifying new opportunities to secure funding through an annual letter campaign, bequests & wills, corporate giving, grants, federal funding, residual income streams, and identifying and nurturing at least one or two new families per year that fundraise for the Association and F.O.P. research;

(b) Finance Committee. The Finance Committee shall consist of 3 to 5 persons, including the Treasurer, who will be a voting member of this committee. The Finance Committee shall monitor the financial affairs of the Association and the performance of the investment managers and report to the Board of Directors quarterly, or more frequently, if needed. The Finance Committee shall alert the Operations Manager and the Chairperson of material deviations from the budget, and make such recommendations it believes will cause the Association to remain reasonably within fiscal responsibility and its budget constraints. The Finance Committee shall develop for approval by the Board of Directors investment goals and criteria for use in the management of the Association's long and short-term investments. Unless otherwise specifically directed in the instrument by which any property is given, bequeathed, conveyed or otherwise transferred to the Association, whether as a fiduciary or otherwise, the Finance Committee shall cause the property so received, or the proceeds there from, to be invested in such investments as, after appropriate investigation and in the prudent exercise of its fiduciary responsibilities, it determines to be advisable and appropriate.

(c) Audit Committee. The Audit Committee shall consist of 3 to 5 persons, including the Treasurer, who is a non-voting member of this committee. The Audit Committee shall ensure that accounting policies and the internal control structure are regularly reviewed and appropriately implemented and that financial statements and reports are issued on time and according to regulatory obligations. Specifically, the Committee shall: 1) recommend an independent audit firm to the Board of Directors; 2) review the scope and plan for the independent audit and recommend any necessary changes; 3) review the previous year's management letter and ensure any issues were corrected by management; 4) review the results of the audit with the external auditor and resolve disagreements between the auditor and management.

(d) Living Independently with Full Equality/LIFE Committee. The LIFE Committee's mission is to help people who have F.O.P. live full, satisfying and independent lives. Using money designated for this purpose, the LIFE Committee sponsors Quality of Life Awards to support and improve the independence and quality of life experienced by qualified applicants, usually by helping purchase mobility devices, training, etc. The LIFE committee shall report to the Board of Directors on its activities on a regular basis, and perform other duties as may from time to time be assigned to it by the Chairperson or the Board.

(e) Board Development Committee. The Board Development Committee shall be selected by the Executive Committee and shall consist of two members of the Board and two from the general Association membership. The Board Development Committee chairperson shall be selected by the Executive Committee and shall be a board member. The Board Development Committee shall recruit qualified individuals from among the Membership of the Association and/or the contacts of said Membership for nomination as members of the Board of Directors in the manner set forth by the Board. The Board Development Committee shall solicit potential directors, investigate their experiences and talents, and develop in the most qualified of these potential nominees an interest in serving on the IFOPA Board of Directors. The development of talented potential board members is a continuing responsibility of the Board Development Committee, in conjunction with the Board of Directors. Consistent with the original goal of the Association of bringing together persons with F.O.P., the Board Development Committee shall, if at all possible, recruit persons with F.O.P. as potential board nominees to ensure that at least two persons with FOP are on the Board at all times, even if one is in an advisory capacity.

(f) Nominating Committee. The Nominating Committee is a subcommittee of the Board Development Committee. The Nominating Committee shall consist of the Board Development Committee chairperson, a current board member selected by the Board Development Committee chairperson, and two past Board members selected by the Nominating Committee chairperson. The Board Development Committee chairperson shall select the Nominating Committee chairperson. The Nominating Committee shall review all applications of Board of Director candidates, interview each candidate by phone and also interview current board members regarding reapplying board members. The Nominating Committee shall, if at all possible, provide nominees to the Board to ensure that at least two persons with FOP are on the Board at all times. The Nominating Committee shall provide the Board with nominees of the number and qualifications requested by the Board in accordance with Section 5.2.

(g) International President's Council. The International President's Council (IPC) serves as a communication system to exchange ideas over international boundaries and identify ways the Association can best serve its international members. The IPC chairperson shall be appointed by the Board Chairperson and shall perform other duties as may from time to time be assigned to it by the Chairperson or the Board.

(h) Jeannie Peeper Awards Selection Committee. Jeannie Peeper IFOPA Awards recognize those who make exceptional contributions to the worldwide FOP community through their leadership, service, fundraising and accomplishments. The Awards Selection Committee is comprised of the following appointees of the board chairman: two persons from the general membership who have been active participants in the FOP community, an IFOPA board member and the IFOPA Operations Manager. The committee chairperson is selected by the committee and shall be one of the two general members. Jeannie Peeper is Honorary Chairperson of the Selection Committee. The committee recommends awardees in each of several categories and the slate is then considered for approval by the Board. Every award is not necessarily given every year and only one award is given in any one category each year.

(i) Communications and PR (C&PR) Committee. The Communications and Public Relations Committee consists of at least two people and works with IFOPA staff to increase awareness and understanding of FOP worldwide. The committee assists staff in creating and updating educational and news materials, and carries out other communication and public relations tasks as needed, employing the full range of media available. The committee particularly strives to reduce the prevailing rate of FOP misdiagnoses and resulting harmful treatments by increasing FOP awareness among doctors, nurses and other clinical care providers. This Committee works in collaboration with the IT and SS&O committees as well as other committees as priorities dictate. The Communications and Membership Manger attends as a guest at the invitation of the committee and works closely with the committee to determine marketing and communications priorities and content. The committee convenes at least quarterly and as needed.

(j) Strategic Staffing and Office Committee: The Strategic Staffing & Office Committee oversees and proactively considers staffing needs and operational improvements in collaboration with the Operations Manager. This Committee is responsible for the office staff and associated requirements, including office lease, equipment, staffing, and importantly linking to technology, C&PR, and other committees as priorities necessitate. Staffing recommendations may include, but are not limited to, change in the number of staff members and adjustments to staff job descriptions, as the nature of the office work dictates. This committee will also organize and conduct annual staff evaluations at the end of each calendar year. The results of which are reported to the board to enable consideration of salary adjustments and other staff issues. This committee is comprised of at least three board members, one of whom shall be the Treasurer. The Operations Manager attends as a guest at the invitation of the committee. The committee convenes at least quarterly and as needed. The Office Liaison chairs this Committee.

(j.2) Office Liaison: Must be a Board Member. The Office Liaison meets with

the IFOPA Operations Manager on a regular and as needed basis. The Office Liaison provides connection to the Board and committees enabling effective communication between the two.

(k) Information Technology (IT) Committee: The Information Technology Committee oversees and proactively considers information technology needs and improvements in collaboration with the Operations Manager. This Committee is responsible for making recommendations for information technology updates, partners, processes, and includes software changes necessary to maintain an efficient and secure office and associated technologies. This Committee is comprised of at least two board members and must maintain close collaboration with the SS&O and C&PR Committees and other committees as priorities dictate. The Operations Manager attends as a guest at the invitation of the committee. The committee convenes at least quarterly and as needed.

(l) Research Committee: The Research Committee is comprised of one or more Board members and one or more volunteers from the FOP community, and IFOPA's Global Research Development Director who collectively liaise with FOP researchers in academic, industry and other institutions worldwide to advance our understanding of FOP, develop therapeutic options, and educate FOP community members worldwide. The Committee supports clinical trial planning and FOP community education and enrollment as needed, registry development, and other research support activities as advised by the Global Research Development Director and the Association's scientific and medical advisors. The committee advises the Board on the allocation of IFOPA funds to support research and the grant allocation process.

Section 8.5 Ad Hoc Committees. The Chairperson, with the approval of the Board as evidenced by resolution, may from time to time create such ad hoc committees as the Chairperson believes necessary or desirable to investigate matters or to advise the Board. Ad hoc committees shall limit their activities to the accomplishment of the tasks for which created and shall have no power to act except as specifically conferred by resolution of the Board. Such committees shall operate until their tasks have been accomplished or until earlier discharged by the Board.

ARTICLE 9

CONTRACTS, LOANS, CHECKS, DEPOSITS, INVESTMENTS

Section 9.1 Contracts and Employment of Agents. The Board of Directors may authorize any director, officer, or agent to enter into any contract, or execute and deliver any instrument, in the name of and on behalf of the Association. The Board of Directors shall be specifically authorized, in its sole discretion, to employ and to pay the compensation of such agents, accountants, custodians, experts, consultants and other counsel, legal, investment, or otherwise, as the Board of Directors shall deem advisable, and to delegate discretionary powers to, and rely upon information furnished by, such individuals or entities. Such authority may be general or confined to specific instances.

Section 9.2 Loans. No loans shall be contracted on behalf of the Association, and no evidences of indebtedness shall be issued in its name, unless authorized by a resolution of the Board of Directors. Such authority may be general or confined to specific instances.

Section 9.3 Checks, Drafts, etc. All checks, drafts, or other orders for the payment of money, notes, or other evidences or indebtedness issued in the name of the Association shall be signed by such officer or officers, agent or agents, of the Association, and in such manner, as shall from time to time be determined by resolution of the Board of Directors.

Section 9.4 Deposits. All funds of the Association not otherwise employed shall be deposited from time to time to the credit of the Association with such banks, trust companies, brokerage accounts, investment managers, or other depositories as the Board of Directors may from time to time select.

Section 9.5 Investment Authority. The Board of Directors shall be authorized to retain assets distributed to the Association, even though such assets may constitute an over-concentration in one or more similar investments. Further, the Board of Directors shall have the authority to make investments in unproductive property, or to hold unproductive property to the extent necessary until it can be converted into productive property at an appropriate time, provided the retention of such property is in the best interest of the Association and does not in any way jeopardize the tax-exempt status of the Association.

ARTICLE 10

STANDARDS OF CONDUCT

Section 10.1 Standards of Conduct. A director or an officer of the Association shall discharge his or her duties as a director or as an officer, including duties as a member of a committee:

10.1.1 In good faith;

10.1.2 With the care an ordinarily prudent person in a like position would exercise under similar circumstances; and

10.1.3 In a manner he or she reasonably believes to be in the best interest of the Association.

Section 10.2 Reliance on Third Parties. In discharging his or her duties, a director or officer is entitled to rely on information, opinions, reports, or statements, including financial statements and other financial data, if prepared or presented by:

10.2.1 One or more officers or employees of the Association whom the director or officer reasonably believes to be reliable and competent in the matters presented;

10.2.2 Legal counsel, public accountants, or other persons as to matters the director or officer reasonably believes are within the person's professional or expert competence; or

- 10.2.3 With respect to a director, a committee of the Board of Directors of which the director is not a member, as to matters within its jurisdiction, if the director or officer reasonably believes the committee merits confidence.

Section 10.3 Bad Faith. A director or officer is not acting in good faith if he or she has knowledge concerning the matter in question that makes reliance otherwise permitted by Section 10.2 unwarranted.

Section 10.4 No Liability. A director or officer is not liable for any action taken, or any failure to take action, as a director or officer, if he or she performs the duties of his or her office in compliance with the provisions of this Article, or if he or she is immune from suit under the provisions of the Act. No repeal or modification of the provisions of this Section 10.4 either directly or by the adoption of a provision inconsistent with the provisions of this Section, shall adversely affect any right or protection, as set forth herein, existing in favor of a particular individual at the time of such repeal or modification.

Section 10.5 Prohibition on Loans. No loans or guarantees shall be made by the Association to its directors or officers. Any director who assents to or participates in the making of any such loan shall be liable to the Association for the amount of such loan until the repayment thereof.

ARTICLE 11

CONFLICTS OF INTEREST

Section 11.1 General. A conflict of interest transaction is a transaction with the Association in which a director or officer of the Association has a direct or indirect interest. A director or officer of the Association has an indirect interest in a transaction if, but not only if, the director or officer is a general partner, director, or officer of another entity in the transaction. A conflict of interest transaction is not voidable or the basis for imposing liability on the director or officer if the transaction was fair at the time it was entered into, or if the transaction is approved as provided in Section 11.2.

Section 11.2 Manner of Approval. A transaction in which a director or officer of the Association has a conflict of interest may be approved if:

- 11.2.1 The material facts of the transaction and the interest of the director or officer were disclosed or known to the Board of Directors, or to a committee consisting entirely of members of the Board of Directors, and the Board of Directors or such committee authorized, approved, or ratified the transaction; or
- 11.2.2 Approval is obtained from the Attorney General of the State of Florida, or from a court of record having equity jurisdiction in an action in which the Attorney General is joined as a party.

Section 11.3 Quorum Requirements. For purposes of Section 11.2 a conflict of interest transaction is authorized, approved, or ratified if it receives the affirmative vote of a majority of

the members of the Board of Directors, who have no direct or indirect interest in the transaction; but a transaction may not be authorized, approved, or ratified under this Article by a single director. A quorum is present for the purpose of taking action under this Article if a majority of the members of the Board of Directors who have no direct or indirect interest in the transaction vote to authorize, approve, or ratify the transaction. The presence of, or vote cast by, a director with a direct or indirect interest in the transaction does not affect the validity of any action taken under subsection 11.2 if the transaction is otherwise approved as provided in Section 11.2.

ARTICLE 12

INDEMNIFICATION AND ADVANCEMENT OF EXPENSES

Section 12.1 Mandatory Indemnification of Directors and Officers. To the maximum extent permitted by the provisions of the Act, as amended from time to time (provided, however, that if an amendment to the Act in any way limits or restricts the indemnification rights permitted by law as of the date hereof, such amendment shall apply only to the extent mandated by law and only to activities of persons subject to indemnification under this Section which occur subsequent to the effective date of such amendment), the Association shall indemnify and advance expenses to any person who is or was a director or officer of the Association, or to such person's heirs, executors, administrators and legal representatives, for the defense of any threatened, pending, or completed action, suit or proceeding, whether civil, criminal, administrative, or investigative, and whether formal or informal (any such action, suit or proceeding being hereinafter referred to as the "Proceeding"), to which such person was, is or is threatened to be made, a named defendant or respondent, which indemnification and advancement of expenses shall include counsel fees actually incurred as a result of the Proceeding or any appeal thereof, reasonable expenses actually incurred with respect to the Proceeding, all fines, judgments, penalties and amounts paid in settlement thereof, subject to the following conditions:

- 12.1.1 The Proceeding was instituted by reason of the fact that such person is or was a director or officer of the Association; and
- 12.1.2 The director or officer conducted himself or herself in good faith, and he or she reasonably believed (i) in the case of conduct in his or her official capacity with the Association, that his or her conduct was in its best interest; (ii) in all other cases, that his or her conduct was at least not opposed to the best interests of the Association; and (iii) in the case of any criminal proceeding, that he or she had no reasonable cause to believe his or her conduct was unlawful. The termination of a proceeding by judgment, order, settlement, conviction, or upon a plea of nolo contendere or its equivalent is not, of itself, determinative that the director or officer did not meet the standard of conduct herein described.

Section 12.2 Permissive Indemnification of Employees and Agents. The Association may, to the maximum extent permitted by the provisions of the Act, as amended from time to time (provided, however, that if an amendment to the Act in any way limits or restricts the indemnification rights permitted by law as of the date hereof, such amendment shall apply only to

the extent mandated by law and only to activities of persons subject to indemnification under this Section which occur subsequent to the effective date of such amendment), indemnify and advance expenses in a Proceeding to any person who is or was an employee or agent of the Association, or to such person's heirs, executors, administrators and legal representatives, to the same extent as set forth in Section 12.1 above, provided that the proceeding was instituted by reason of the fact that such person is or was an employee or agent of the Association and met the standards of conduct set forth in Subsection 12.1.2 above. The Association may also indemnify and advance expenses in a Proceeding to any person who is or was an employee or agent of the Association to the extent, consistent with public policy, as may be provided by these By-Laws, by contract, or by general or specific action of the Board of Directors.

Section 12.3 Non-Exclusive Application. The rights to indemnification and advancement of expenses set forth in Sections 12.1 and 12.2 above are contractual between the Association and the person being indemnified, and his or her heirs, executors, administrators and legal representatives, and are not exclusive of other similar rights of indemnification or advancement of expenses to which such person may be entitled, whether by contract, by law, by a resolution of the Board of Directors, by these By-Laws, by the purchase and maintenance by the Association of insurance on behalf of a director, officer, employee, or agent of the Association, or by an agreement with the Association providing for such indemnification, all of which means of indemnification and advancement of expenses are hereby specifically authorized.

Section 12.4 Non-Limiting Application. The provisions of this Article shall not limit the power of the Association to pay or reimburse expenses incurred by a director, officer, employee, or agent of the Association in connection with such person's appearing as a witness in a Proceeding at a time when he or she has not been made a named defendant or respondent to the Proceeding.

Section 12.5 Prohibited Indemnification. Notwithstanding any other provision of this Article, the Association shall not indemnify or advance expenses to or on behalf of any director, officer, employee, or agent of the Association, or such person's heirs, executors, administrators or legal representatives:

- 12.5.1 If a judgment or other final adjudication adverse to such person establishes his or her liability for any breach of the duty of loyalty to the Association, for acts or omissions not in good faith or which involve intentional misconduct or a knowing violation of law, or under the Act; or
- 12.5.2 In connection with a Proceeding by or in the right of the Association in which such person was adjudged liable to the Association; or
- 12.5.3 In connection with any other Proceeding charging improper personal benefit to such person, whether or not involving action in his or her official capacity, in which he or she was adjudged liable on the basis that personal benefit was improperly received by him or her.

Section 12.6 Repeal or Modification Not Retroactive. No repeal or modification of the provisions of this Article, either directly or by the adoption of a provision inconsistent with the provisions of this Article, shall adversely affect any right or protection, as set forth herein, existing in favor of a particular individual at the time of such repeal or modification.

ARTICLE 13

NOTICES AND WAIVER OF NOTICE

The notices provided for in these By-Laws shall be communicated in person, by telephone, electronic mail, facsimile, or by mail or private carrier. Written notice is effective at the earliest of (a) receipt, (b) five (5) days after its deposit in the United States mail, if mailed correctly addressed and with first-class postage affixed thereon, (c) on the date shown on the return receipt, if sent by registered or certified mail, return receipt requested, and the receipt is signed by or on behalf of the addressee, or (d) twenty (20) days after its deposit in the United States mail, if mailed correctly addressed, and with other than first-class, registered, or certified postage affixed. Whenever any notice is required to be given to any director, officer, or committee member of the Association under the provisions of these By-Laws, or the Act, a waiver thereof in writing signed by the person or persons entitled to such notice, whether before or after the time stated therein, shall be deemed equivalent to the giving of such notice.

ARTICLE 14

FISCAL YEAR

The fiscal year of the Association shall end on the 31st day of December, or on such other date as may be fixed from time to time by the Board of Directors.

ARTICLE 15

AMENDMENTS

These By-Laws may be altered, amended, or repealed, and new By-Laws adopted, upon the affirmative vote of two-thirds (2/3) of the Board of Directors of the Association at any annual or special meeting, except to the extent that such alteration, amendment, or repeal is inconsistent with Article 15 hereof.

ARTICLE 16

EXEMPT STATUS

The Association has been organized and will be operated exclusively for exempt purposes within the meaning of Section 501(c)(3) of the Code and, as such, will be exempt from taxation under Section 501(a) of the code. Any provision of these By-Laws or of the Charter which would in any manner adversely affect the Association's tax-exempt status shall be void and shall be

deleted or modified as necessary to comply with all applicable federal and state requirements for the maintenance of the Association's tax-exempt status.

These revised and reworded By-Laws are adopted and shall be effective this 14th day of July, 2015.

A handwritten signature in black ink that reads "Karen Munro". The signature is written in a cursive style with a long horizontal flourish at the end.

Karen E. Munro, Secretary