CONFLICT OF INTEREST POLICY
OF
EVERYLIFE FOUNDATION FOR RARE DISEASES

ARTICLE I
PURPOSE

The purpose of this conflict of interest policy is to protect the interest of EveryLife Foundation for Rare Diseases (the “Organization”) when it is contemplating entering into a transaction or arrangement that might benefit the private interest of an officer, a director, or a key employee of the Organization or might result in a possible excess benefit transaction. This policy is intended to supplement but not replace any applicable state and federal laws governing conflict of interest applicable to nonprofit and charitable organizations.

ARTICLE II
DEFINITIONS

1. Interested Persons

Any director, principal officer, or key employee who has a direct or indirect financial interest, as defined below, is an interested person.

A key employee is an employee whose total annual compensation (including benefits) from the Organization and its affiliates is more than $150,000 and who:

(a) Has responsibilities or influence over the Organization similar to that of officers, directors, or trustees;
(b) Manages a program that represents 10% or more of the activities, assets, income, or expenses of the Organization; or
(c) Has or shares authority to control 10% or more of the Organization’s capital expenditures, operating budget, or compensation for employees.

2. Financial Interest

A person has a financial interest if the person has, directly or indirectly, through business, investment, or family:

(a) An ownership or investment interest in any entity with which the Organization has a transaction or arrangement,
(b) A compensation arrangement with the Organization or with any entity or individual with which the Organization has a transaction or arrangement, or
(c) A potential ownership or investment interest in, or compensation arrangement with, any entity or individual with which the Organization is negotiating a transaction or arrangement.

Compensation includes direct and indirect remuneration as well as gifts or favors that are not insubstantial.

A financial interest is not necessarily a conflict of interest. Under Article III, Section 2, a person who has a financial interest may have a conflict of interest only if the appropriate governing board or board committee decides that a conflict of interest exists.

ARTICLE III
PROCEDURES

1. Duty to Disclose

In connection with any actual or possible conflict of interest, an interested person must disclose the existence of the financial interest and be given the opportunity to disclose all material facts to the governing board or board committee members considering the proposed transaction or arrangement.

2. Determining Whether a Conflict of Interest Exists

After disclosure of the financial interest and all material facts and after any discussion with the interested person, he/she shall leave the governing board or board committee meeting while the determination of a conflict of interest is discussed and voted upon. The remaining governing board or board committee members shall decide if a conflict of interest exists.

3. Procedures for Addressing the Conflict of Interest

(a) An interested person may make a presentation at the governing board or board committee meeting, but after the presentation, he/she shall leave the meeting during the discussion of, and the vote on, the transaction or arrangement involving the possible conflict of interest.

(b) The chairperson of the governing board or board committee shall, if appropriate, appoint a disinterested person or committee to investigate alternatives to the proposed transaction or arrangement.

(c) After exercising due diligence\(^1\), the governing board or board committee shall determine whether the Organization can obtain with reasonable efforts a more advantageous

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\(^1\) A review of appropriate comparability data is required if the board wants to avail itself of the presumption of reasonableness under Internal Revenue Code Section 4958. In that case, the minutes must document the terms of the transaction, the date approved, and the comparability data obtained and relied upon, as well as the information described in Article IV.
transaction or arrangement from a person or entity that would not give rise to a conflict of interest.

(d) If a more advantageous transaction or arrangement is not reasonably possible under circumstances not producing a conflict of interest, the governing board or board committee shall determine by a majority vote of the disinterested directors whether the transaction or arrangement is in the Organization’s best interest, for its own benefit, and whether it is fair and reasonable. In conformity with the above determination, it shall make its decision as to whether to enter into the transaction or arrangement.

4. Violations of the Conflicts of Interest Policy

(a) If the governing board or board committee has reasonable cause to believe an interested person has failed to disclose actual or possible conflicts of interest, it shall inform the interested person of the basis for such belief and afford the interested person an opportunity to explain the alleged failure to disclose.

(b) If, after hearing the interested person’s response and after making further investigation as warranted by the circumstances, the governing board or board committee determines the interested person has failed to disclose an actual or possible conflict of interest, it shall take appropriate disciplinary and corrective action.

ARTICLE IV
RECORDS OF PROCEEDINGS

The minutes of the governing board and all board committees shall contain:

(a) The names of the persons who disclosed or otherwise were found to have a financial interest in connection with an actual or possible conflict of interest, the nature of the financial interest, any action taken to determine whether a conflict of interest was present, and the governing board’s or board committee’s decision as to whether a conflict of interest in fact existed.

(b) The names of the persons who were present for discussions and votes relating to the transaction or arrangement, the content of the discussion, including any alternatives to the proposed transaction or arrangement, and a record of any votes taken in connection with the proceedings.

ARTICLE V
COMPENSATION

(a) A voting member of the governing board who receives compensation, directly or indirectly, from the Organization for services is precluded from voting on matters pertaining to that member’s compensation.

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2 If a director is the interested person and the transaction is a self-dealing transaction pursuant to California Corporations Code Section 5233, the determination must be made by a vote of a majority of the directors then in office without counting the vote of the interested director or directors.
(b) A voting member of any committee whose jurisdiction includes compensation matters and who receives compensation, directly or indirectly, from the Organization for services is precluded from voting on matters pertaining to that member’s compensation.

(c) No voting member of the governing board or any committee whose jurisdiction includes compensation matters and who receives compensation, directly or indirectly, from the Organization, either individually or collectively, is prohibited from providing information to any committee regarding compensation.

ARTICLE VI
ANNUAL STATEMENTS

Each director, principal officer, and key employee shall annually sign a statement which affirms such person:

(a) Has received a copy of the conflict of interest policy,
(b) Has read and understands the policy,
(c) Has agreed to comply with the policy, and
(d) Understands that the Organization is charitable and in order to maintain its federal tax exemption it must engage primarily in activities which accomplish one or more of its tax-exempt purposes.

ARTICLE VII
PERIODIC REVIEWS

To ensure that the Organization operates in a manner consistent with charitable purposes and does not engage in activities that could jeopardize its tax-exempt status, periodic reviews shall be conducted. The periodic reviews shall, at a minimum, include the following subjects:

(a) Whether compensation arrangements and benefits are reasonable, based on competent survey information, and the result of arm’s length bargaining.
(b) Whether partnerships, joint ventures, and arrangements with management organizations conform to the Organization’s written policies, are properly recorded, reflect reasonable investment or payments for goods and services, further charitable purposes, and do not result in inurement, impermissible private benefit, or an excess benefit transaction.

ARTICLE VIII
USE OF OUTSIDE EXPERTS

When conducting the periodic review as provided for in Article VII, the Organization may, but need not, use outside advisors. If outside experts are used, their use shall not relieve the governing board of its responsibility for ensuring periodic reviews are conducted.
ANNUAL AFFIRMATION AND DISCLOSURE STATEMENT

Pursuant to EveryLife Foundation for Rare Diseases’ (the “Organization”) Conflict of Interest Policy (the “Policy”), I acknowledge, attest, and represent the following:

1. I have received and read a copy of the Policy.

2. I understand and agree to comply with the Policy.

3. I understand that the Organization is charitable, and in order to maintain its federal tax exemption, it must engage primarily in activities which accomplish one or more of its tax-exempt purposes.

4. Reported below, or by attached list, are:

   (a) All financial interests that could give rise to a conflict, such as transactions between the Organization and me, or the Organization and a family member;

   (b) My affiliations with any organization with which the Organization may have a financial relationship; and

   (c) Family members who are affiliated with any organization with which the Organization may have a financial relationship.

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Signature                   Date

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Printed Name, Title