



COFFIN-LOWRY SYNDROME FOUNDATION CONFLICT OF INTEREST POLICY

PREAMBLE

The Coffin-Lowry Syndrome Foundation (CLSF) seeks to operate to the highest possible level of public accountability and disclosure. It is therefore appropriate for all members of the Board of Directors and other associated persons to disclose any real or potentially perceivable conflicts of interest.

This policy document is intended to assist members of the Board of Directors, officers, and members of any committee of CLSF with Board-delegated powers to identify and act appropriately in situations that present actual and/or potential conflicts of interest of many types, and to provide CLSF with procedures which, when properly observed and acted upon, will allow such conflicts of interest to be addressed and managed in ways that comply with applicable federal and state laws and CLSF's status as a highly visible, nationally and internationally active, charitable organization.

All members of the Board of Directors, officers, and members of any Committee of CLSF with Board-delegated powers are required to act in full accordance with this policy and always to declare any possible conflicts of interest, including those that might be perceived by third parties, so that CLSF's Board of Directors and officers may make appropriate decisions about whether an actual conflict of interest does in fact exist – or could reasonably be thought to exist.

Please note that the existence of conflict of interests as defined in this policy does not necessarily suggest or imply that an individual cannot act as a member of CLSF's Board of Directors, or as a member of any committee of CLSF with Board-delegated powers. What is of importance is that all such actual or potential conflicts of interest are appropriately acknowledged and managed. However, certain types of conflicts of interest may lead the Board of Directors or the Executive Committee of CLSF to determine that an individual is not eligible to become a member of the Board or should be asked to step down as a member of CLSF's Board.

ARTICLE I - PURPOSE

1. Purposes of the policies and procedures defined herein are:
 - a. To protect CLSF's interests when it is contemplating entering into a transaction or arrangement that might benefit the private interests of an officer or director of CLSF or might result in a possible excess benefit transaction;
 - b. To assure the integrity of CLSF's position in the public policy environment;

- c. To assure the transparency of CLSF's processes in all decision-making in accordance with its mission and vision.
2. This policy is intended to supplement, but not replace, state and federal laws governing conflicts of interest applicable to nonprofit and charitable organizations.
3. This policy is also intended to define and identify "independent" directors.

ARTICLE II - DEFINITIONS

Conflict of Interest

For purposes of this policy, the following circumstances shall be deemed to create actual or potential conflicts of interest:

- a. Outside Interests
 - i. A contract or transaction between CLSF and a responsible person or family member.
 - ii. A contract or transaction between CLSF and any entity in which a responsible person or family member has a material financial interest or of which such person is a director, officer, agent, partner, associate, trustee, personal representative, receiver, guardian, custodian, conservator, or other legal representative.
- b. Outside Activities
 - i. A responsible person competing with CLSF in the rendering of services or in any other contract or transaction with a third party
 - ii. A responsible person having a material financial interest in, or serving as a director, officer, agent, partner, associate, trustee, personal representative, receiver, guardian, custodian, conservator, or other legal representative of or consultant to, an entity or individual that competes with CLSF in the provision of services or in any other contract or transaction with a third party.
 - iii. A responsible person or family member having a policy interest that conflicts with public policy positions taken by CLSF in the rare disease, orphan drug, and/or orphan device policy environment.
- c. Gifts, Gratuities, and Entertainment

A responsible person accepting gifts, entertainment, or other favors from any individual or entity that:

- i. Does or is seeking to do business with, or is a competitor of CLSF;
- ii. Has received, is receiving, or is seeking to receive a loan or grant, or to secure other financial commitments from CLSF;
- iii. Is a charitable organization with a similar mission to that of CLSF, whether in whole or in part;
- iv. Under circumstances where it might be inferred that such action was intended or possibly would influence the responsible person in the performance of his or her duties.

This does not preclude the acceptance of items of nominal (under US \$25.00 or foreign currency equivalent) or insignificant value which are not related to any particular transaction or activity of CLSF.

1. Other Definitions

- a. *Responsible Person*: any person serving as a member of the Board of Directors of CLSF, an officer, or a member of any committee of CLSF with Board-delegated powers.
- b. *Family Member*: a spouse, domestic partner, parent, child or spouse or domestic partner of a child, brother, sister, or spouse or domestic partner of a brother or sister, of a responsible person.
- c. *Material Financial Interest*: a financial interest of any kind in any entity, which, in view of the circumstances, is substantial enough that it would, or reasonably could, affect a responsible person's or family member's judgment with respect to transactions to which the entity is a party, specifically including:
 - An ownership or investment interest in any entity with which CLSF has a transaction or arrangement;
 - A compensation arrangement with CLSF or with any entity or individual with which CLSF has a transaction or arrangement;
 - A potential ownership or investment interest in/or compensation arrangement with, any entity or individual with which CLSF is negotiating a transaction or arrangement.
- d. *Compensation*: includes direct and indirect remuneration as well as gifts or favors that are not insubstantial.

Note: A Material financial interest is not necessarily a conflict of interest. A person who has a material financial interest may have a conflict of interest only if the Board of Directors or Executive Committee of CLSF decides that a conflict of interest exists, in accordance with this policy.

- e. *Contract or Transaction*: any agreement or relationship involving the sale or purchase of goods, services, rights of any kind, the providing or receipt of a loan or grant, or the establishment of any other type of pecuniary relationship. The making of a gift to CLSF is not a contract or transaction.
- f. *Policy Interest*: an interest created by employment by or because of membership of any other organization that takes public policy positions in the rare disease/orphan drug and device policy environment.

Note: A policy interest is not necessarily a conflict of interest. A person with a policy interest may have a conflict only if the Board of Directors or Executive Committee of CLSF decides that a conflict of interest exists, in accordance with this policy.

- g. *Independent Director*: Any member of the Board of Directors of CLSF shall be considered an "independent director" for the purposes of this policy if he or she is "independent" as defined in the instructions for the IRS 990 form or, until such definition is available, the director:
 - Is not, and has not been for a period of at least three years, an employee of CLSF or any entity in which CLSF has a financial interest;
 - Does not directly or indirectly have a significant business relationship with CLSF, which might affect independence in decision-making;

- Is not employed as an executive of another corporation where any of CLSF's executive officers or employees serve on that corporation's compensation committee; and
- Does not have an immediate family member who is an executive officer or employee of CLSF or who holds a position that has a significant financial relationship with CLSF.

ARTICLE III - PROCEDURES

1. Duty to Disclose

In connection with any actual or potential conflict of interest, including personal conflicts of interest and those of family members, any responsible person must disclose the existence of any material financial interest and/or policy interest and be given the opportunity to disclose all material facts to the Board or the Executive Committee.

2. Disclosure Prior to Action

Prior to any Board or Board-responsible committee action on a contract or transaction, any responsible person having an actual conflict of interest and who is in attendance at the meeting shall disclose all facts material to the conflict of interest. Such disclosure shall be reflected in the minutes of the meeting.

3. Recusal of Self

Any responsible person may recuse him- or herself at any time from involvement in any discussion or decision in which the responsible person believes he or she has or may have a conflict of interest, without going through the process for determining whether a conflict of interest exists. However, any responsible person who plans to not attend a meeting at which he or she has reason to believe that the Board of Directors or any committee with Board-delegated powers will act on a matter in which the responsible person has an actual (as opposed to a possible) conflict of interest shall disclose to the chair of the meeting all facts material to the conflict of interest. The chair shall report the disclosure at the meeting and the disclosure shall be reflected in the minutes of the meeting.

4. Determination as to Whether a Conflict of Interest Exists

After disclosure of any potential material financial interest and/or policy interest and all material facts by the responsible person, the remaining Board or Executive Committee members shall determine whether a conflict of interest exists according to the following process and procedures:

- a. The responsible person may make a presentation at the Board or Executive Committee meeting, but, after this presentation, he/she shall leave the meeting during the discussion of, and the vote on, the transaction, arrangement, or policy matter involving the possible conflict of interest.
- b. The Chairperson of the Board or Executive Committee shall, if appropriate, appoint a disinterested person or committee to investigate alternatives to any proposed financial transaction or arrangement.
- c. After exercising due diligence, and when relevant, the Board or Executive Committee shall determine whether CLSF can, with reasonable efforts, secure a more advantageous transaction or arrangement from a person or entity that would not give rise to a conflict of interest.

- d. When relevant, if a more advantageous transaction or arrangement is not reasonably possible under circumstances not producing a conflict of interest, the Board or Executive Committee shall determine by a majority vote of the disinterested directors whether the transaction or arrangement is in CLSF'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.

5. Violations of the Conflicts of Interest Policy

- a. Should the Board or Executive Committee have reasonable cause to believe a responsible person has failed to disclose actual or reasonably foreseeable conflicts of interest, it shall inform the responsible person of the basis for such belief and afford the responsible person an opportunity to explain the alleged failure to disclose.
- b. If, after hearing the responsible person's response and after making further investigation as warranted by the circumstances, the Board or Executive Committee determines the member has failed to disclose an actual or possible conflict of interest, the Board or Executive Committee shall take appropriate disciplinary and corrective action.

ARTICLE IV – RECORDS OF PROCEEDINGS

1. Meeting Minutes

The minutes of the Board and of all committees with Board-delegated powers shall contain:

- a. The names of the persons who disclosed or otherwise were found to have a material financial interest and/or policy interest, the nature of the interest, any action taken to determine whether a conflict of interest was present, and the Board's or Executive 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 matter, the content of the discussion, including any alternatives to a proposed financial transaction or arrangement, and a record of any votes taken in connection with the proceedings.

ARTICLE V – COMPENSATION

1. Voting Restrictions

- a. Any responsible person who receives compensation, directly or indirectly, from CLSF for services is precluded from voting on matters pertaining to that member's compensation.
- b. Any responsible person serving as a member of any Board-responsible committee whose jurisdiction includes compensation matters and who receives compensation, directly or indirectly, from CLSF for services is precluded from voting on matters pertaining to that responsible person's compensation.

2. Providing Information to Committee Regarding Compensation

A responsible person serving as a member of a Board-responsible committee whose jurisdiction includes compensation matters and who receives compensation, directly or indirectly, from CLSF, either individually or collectively, is not prohibited from providing information to any committee regarding compensation.

ARTICLE VI – ANNUAL STATEMENTS

1. Annual Affirmation - All

Every responsible person shall annually sign a statement which affirms that such person:

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

2. Annual Affirmation – Board of Directors

Every member of the Board of Directors shall annually sign a statement which declares whether such person is an independent director.

3. Changes to Affirmations

If at any time during the year the information in the annual statement changes materially, the responsible person shall disclose such changes and revise the annual disclosure form.

4. Compliance

The Executive Committee shall regularly and consistently monitor and enforce compliance with this policy by reviewing annual statements and by taking such other actions as are necessary for effective oversight.

ARTICLE VII – CONFIDENTIALITY

Every responsible person shall exercise appropriate care to not disclose confidential information acquired in connection with such status or information the disclosure of which might be adverse to the interests of CLSF. Furthermore, a responsible person shall not disclose or use information relating to the business of CLSF for the personal profit or advantage of the responsible person or any family member.

ARTICLE VII – CONFIDENTIALITY

To ensure that CLSF operates in a manner consistent with its 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 any and all compensation arrangements and benefits are reasonable, based on competent survey information (if reasonably available), and the result of arm's length bargaining.
- b. Whether partnerships, joint ventures, and arrangements with management of organizations, if any, conform to CLSF's written policies, are properly recorded, reflect reasonable investment or payments for goods and services, further

charitable purposes, and do not result in inurement or impermissible private benefit or in an excess benefit transaction.

ARTICLE IX – USE OF OUTSIDE EXPERTS

When conducting the periodic reviews as provided for in Article VIII, CLSF may, but need not, use outside advisors. If outside experts are used, their use shall not relieve the Board of its responsibility for ensuring periodic reviews are conducted.