



International WAGR Syndrome Association Board of Directors Responsibilities and Expectations

adopted November, 2017

Purpose

The International WAGR Syndrome Association (IWSA) Board of Directors governs the organization's strategic and organizational management. The IWSA BOD are committed to furthering the International WAGR Syndrome Association's mission to promote awareness, stimulate research, and support families affected by WAGR syndrome.

Structure

Composition: Members of the Board of Directors will include individuals with a diverse range of professional and personal backgrounds to support the needs of the organization. The Board of Directors will consist of between five (5) and twelve (12) members, who have been invited to serve by the active Board of Directors of the International WAGR Syndrome Association.

Eligibility: Members of the Board of Directors must be passionate about International WAGR Syndrome Association's mission, goals, objectives and values. Selected Board of Directors will have achieved leadership stature in business, government, philanthropy, or the nonprofit sector. Individuals should be professionals with accomplishments that can be documented by reputation, publication, *and/or by direct experience with and knowledge of WAGR syndrome.*

Terms: Board of Directors members will serve for terms of three (3) years. Members may serve two (2) consecutive terms. There is no limit to the total number of terms, but after two (2) consecutive terms, an optional sabbatical is strongly encouraged. Members may serve in another capacity before returning to the Board. Terms will be staggered* A member of the Board of Directors may resign by submitting a written notice to the International WAGR Syndrome Association Board of Directors. At any regular meeting or special meeting called for this

purpose, the International WAGR Syndrome Association Board of Directors may fill a vacancy on the Board of Directors by electing a new member.

Removal: A member of the Board may be removed from office by a two-thirds majority vote of the Board of Directors at a regularly scheduled meeting.

Leadership: The Chairman of the Board of Directors will be elected for a two-year (2) term from its membership, by its members, to serve in the leadership role. In the event of the Chairman position vacancy, election of a new Chairman will be held at any Board of Directors meeting. This action must be ratified by the International WAGR Syndrome Association Board of Directors in order to be official. At the end of his/her term, the Chairman may be elected to serve another term, with a limit of two (2) consecutive terms permitted.

The Secretary of the Board of Directors will be an existing member of the Board, elected by the members of the Board of Directors. The Secretary of the Board of Directors is responsible for recording minutes of all Board of Directors proceedings; distributing them to Board members, filing the minutes in the appropriate organizational location, and performing any other relevant duties at the request of the Chairman of the Board. Election of a Secretary can be held at any Board of Directors meeting.

Operation

Meetings: Board of Directors meetings will be held at least quarterly. Board members must attend and participate in at least three meetings per year. Most board meetings will be held by teleconference and video call, at times and in places determined by the Executive Director or the Board of Directors. In-person Board meetings may be held during WAGR Weekend, the IWSA's annual family gathering, or during other organization-planned meetings.

These arrangements will be made with an eye toward both convenience of attendance and low cost. Special meetings of the Board of Directors can be called by notifying all members of the Board of Directors at least forty-eight (48) hours before the meeting, noting the time, place or details of the conference call, and the agenda or purpose of the meeting. A quorum is defined as a majority of the members then in office. A vote equal to or greater than the majority of members then in office and voting shall be required to carry any motion. Votes may be cast in person, by phone, by fax, by e-mail, or by proxy (if organized in advance).

Compensation: Members of the Board of Directors will receive no compensation for their time or their expertise. Board of Directors members will be reimbursed, however, for expenses that are incurred in order to fulfill their specific responsibilities to International WAGR Syndrome Association, as long as these expenses are reasonable and appropriate, *are authorized ahead of time*, are presented to the Treasurer according to IWSA policy, and are not covered by other means.

Organization Participation: Board of Directors must participate in a minimum of one activity (project or event) of the International WAGR Syndrome Association event every 12 months. Board of Directors must contribute content for one blog post per 12-month period.

Operating Guidelines: These operating guidelines may be changed only by a vote of the International WAGR Syndrome Association Board of Directors, though recommendations for changes will be welcome from the Board of Directors itself.

Roles and Responsibilities

The Board of Directors will support the work of International WAGR Syndrome Association and provide mission-based leadership and strategic governance. While day-to-day operations are led by International WAGR Syndrome Association's Executive Director (ED), the Board of Directors - Executive Director relationship is a partnership, and the appropriate involvement of the Board is both critical and expected.

Board Member responsibilities include:

Leadership, governance and oversight

- Serving as a trusted advisor to the ED as s/he develops and implements International WAGR Syndrome Association's strategic plan
- Reviewing outcomes and metrics created by International WAGR Syndrome Association for evaluating its impact, and regularly measuring its performance and effectiveness using those metrics
- Reviewing agenda and supporting materials prior to board and committee meetings
- Contributing one blog article per 12-month period as an update, review, or psychosocial article
- Approving International WAGR Syndrome Association's annual budget, audit reports, and material business decisions; being informed of, and meeting all, legal and fiduciary responsibilities
- Partnering with the ED and other Board members to ensure that board resolutions are carried out
- Representing International WAGR Syndrome Association to stakeholders; acting as an ambassador for the organization

Fundraising

International WAGR Syndrome Association Board of Directors will consider International WAGR Syndrome Association a philanthropic priority and make annual gifts that reflect that priority. International WAGR Syndrome Association expects to have 100 percent of Board of Directors

make an annual contribution *that is commensurate with their capacity* through direct donation or hosted fundraising event.

Ideal candidates will have the following qualifications:

- Professional experience with significant executive leadership accomplishments in business, philanthropy, or the rare disease community sector
- A commitment to and understanding of International WAGR Syndrome Association's beneficiaries
- Diplomatic skills and a natural affinity for cultivating relationships and persuading, convening, facilitating, and building consensus among diverse individuals
- Personal qualities of integrity, credibility, and a passion for improving the lives of International WAGR Syndrome Association's beneficiaries

Board Chair Job Description

- Oversees board meetings
- Works in partnership with the Executive Director to make sure board resolutions are carried out
- Calls special meetings if necessary
- Appoints all committee chairs, and with the Executive Director, recommends who will serve on committees
- Assists Executive Director in preparing agenda for board meetings
- Assists Executive Director in conducting new board member orientation
- Oversees searches for a new Executive Director
- Coordinates Executive Director's annual performance evaluation
- Works with the Executive Committee to recruit new Board of Directors
- Acts as an alternate spokesperson for the organization
- Periodically consults with Board of Directors on their roles and helps them assess their performance

Board Vice Chair Job Description

- Attend all board meetings
- Carry out special assignments as requested by the board chair
- Understand the responsibilities of the board chair and be able to perform these duties in the chair's absence
- Participate as a vital part of the board leadership

Board Secretary Job Description

- Attend all board meetings
- Ensure the safety and accuracy of all board records

- Record, distribute, and file board minutes
- Assume responsibilities of the chair in the absence of the board chair, chair-elect, and vice chair
- Provide notice of meetings of the board and/or of a committee when such notice is required

Board Treasurer Job Description

- Attend all board meetings
- Maintain knowledge of the organization and personal commitment to its goals and objectives
- Understand financial accounting for nonprofit organizations
- Manage the board's review of and action related to the board's financial responsibilities
- Work with the Executive Director to ensure that appropriate financial reports are made available to the board on a timely basis
- Present the annual budget to the board for approval
- Review the annual audit and answer Board of Directors' questions about the audit

I have read the above and agree to fulfill these Responsibilities to the best of my ability.

Signed _____

Date _____