



International WAGR Syndrome Association

Fundraising Policy

Thank you for your interest in raising funds to support the International WAGR Syndrome Association (IWSA). Our success depends on the initiative of supporters like you. Each dollar t raised helps the IWSA to stimulate research on WAGR syndrome, to reach out to those affected, and to provide vital information on WAGR syndrome to families and physicians.

Whether you've hosted fundraising events in the past or are new to fundraising, this Fundraising Policy is designed to help you effectively raise money and awareness for the IWSA. Please carefully review this document as it contains important guidelines to follow when raising money on behalf of IWSA.

The IWSA has the privilege of being recognized by the Internal Revenue Service (IRS) as a tax-exempt charitable organization; this tax exempt status is crucial for our ability to carry out the organization's mission. In order to preserve this status, it is essential that you comply with various IRS regulations regarding nonprofit fundraising activities.

IWSA representatives are available to help make your event as easy and successful as possible. If you have questions or need support, contact the IWSA at reachingout@wagr.org

Third Party Events

A “Third-Party Event” is defined as any fundraising activity conducted by a group or individual that is not employed by IWSA, where IWSA has no fiduciary responsibility and little or no staff involvement in its execution. These policies pertain to all events or activities benefiting IWSA that are organized and executed by third parties.

Organizer Responsibilities

- All expenses are the responsibility of the event organizer. IWSA is not responsible for any expenses incurred for a third-party fundraising activity, and will not advance funds or reimburse expenses unless approved in advance by the Board of Directors. We recommend finding event sponsors or charging a registration fee to help cover expenses. You may not purchase goods or services under IWSA’s name, and IWSA sales tax-exemption (on purchases) cannot be extended to any third-party event or fundraising effort.
- The event organizer is responsible for the planning and execution of the event including safety precautions and adherence to applicable laws. As the beneficiary of a fundraising event, IWSA does not accept or assume any liability associated with the event including but not limited to any injuries sustained by event volunteers or participants during the event. The event organizer will indemnify, defend, and hold harmless IWSA, its directors, officers, and employees from any and all claims that may arise out of or relate to such event.
- The event organizer is responsible for obtaining all applicable permits or licenses, including but not limited to alcohol, solicitation, and sales tax licenses.
- The event organizer may not keep any portion of the proceeds (beyond real expenses) as profit or compensation for organizing the event.
- The event organizer may not set up a temporary bank account in IWSA’s name, as this is illegal.
- Donors must be informed that the tax deductible amount of a donation is only the amount that is over and above the value of any goods or services received in exchange for the donation. For example, if a participant pays \$200 to participate in a golf outing, and the value of the outing is \$50, the donation amount is \$150. If a donor pays less than the value of an item then they will not receive a tax deduction.
- If goods are sold to raise money as part of a fundraising event it must be made clear to the event participants what percentage of the sale price benefits IWSA.

Promotion & Publicity

- All third party events must be publicized and conducted in a manner that makes it clear that IWSA is the beneficiary, not the sponsor or host of the event.
- Promotional materials must clearly state that the event is raising funds that will benefit IWSA (e.g. “proceeds benefit the International WAGR Syndrome Association”).
- Event names may not incorporate the name of IWSA, as in “The IWSA Walk-a-thon.” IWSA’s name may be used in a second clause identifying the relationship of the event with the IWSA, such as “John Doe Walk-a-thon, benefitting IWSA.”

- All event materials that include IWSA's logo, including, but not limited to, advertising, press releases, posters, flyers, t-shirts, and public service announcements, must be reviewed and approved prior to distribution.

IWSA Responsibilities

- The IWSA will comply with all federal, state and local laws concerning fundraising practices.
- The IWSA and its representatives are responsible for conducting fundraising activities in a manner that upholds the public and donors' trust in stewardship of contributed funds.
- Fundraising communications on behalf of the IWSA will include clear, accurate and honest information about the organization, its activities and the intended use of funds.
- The IWSA will use funds consistent with donor intent and comply with specific conditions placed upon donations.
- The IWSA will send a written acknowledgement to all donors within 14 days of receipt of donation.
- The IWSA will strive for a balance between publicly recognizing charitable contributions and maintaining donor confidentiality when requested. **The IWSA will not share, trade or sell contact information for any donor.**
- The IWSA will decline funds or in-kind donations that would bring about adverse conditions for the organization or its constituents and gifts given for purposes outside the scope of its mission.
- The IWSA will closely monitor any individual or organization that solicits funds on its behalf to ensure adherence to donor intent as well as accountable fundraising practices.
- The IWSA will regularly communicate with contributors regarding activities and programs and will make such information available through public and private media (including the wagr.org website, IWSA private and public Facebook groups, WAGR Warrior newsletter, annual reports, and WAGR Weekend events).
- **The IWSA will not participate in fundraisers which raise money for individuals. Use of the IWSA name, logo, or any text or image meant to imply the participation of the IWSA in a fundraiser in which any portion of the proceeds are designated for an individual is not permitted.**

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Revised February 2020