



International WAGR Syndrome Association

Volunteer Handbook

*"I am only one,
but still I am one.
I cannot do everything,
but still I can do something."
~ Helen Keller*

Table of Contents

Introduction

Mission
Operating Principles
Who's Who at IWSA

Becoming a Volunteer

Placement and Use of Volunteers
Management of Volunteers
Recognition and Awards
Liability
Discrimination Policy
Sexual Harassment Policy
Dispute Resolution

Conduct Guidelines: Representing the International WAGR Syndrome Association

Email Guidelines
Communication and Transparency
Social Media Guidelines
Online or Written Communication
Patient Support
Use and Copyright of Website
Code of Conduct
Conflict of Interest
Confidentiality
Planning Your Event
Event Liability
Finances
Sponsorships
Receipting and Tax-Deductibility of Charitable Donations to 501(c)(3)

The IWSA Volunteer Code of Conduct

Code of Ethics
Conflict Resolution Policy

INTRODUCTION

The International WAGR Syndrome Association (the "IWSA") appreciates those who wish to give of their time and talents for the benefit of the organization and its goals. The purpose of this Volunteer Handbook is to explain daily operations, policies and procedures, and provide overall guidance for any individual wishing to volunteer for the IWSA.

Volunteers are expected to carry out their responsibilities to the best of their ability, in accordance with our Code of Conduct policy, while upholding the IWSA mission and adhering to these policies. Your role as a volunteer is critical to the mission of the IWSA.

"Paul Revere made his living as a silversmith. But he's remembered for what he did as a volunteer."

MISSION

The International WAGR Syndrome Association's mission is to **promote awareness, stimulate research and support families affected by WAGR syndrome.**

OPERATING PRINCIPLES

Volunteers of the International WAGR Syndrome Association are guided by four main principles. We will always strive to:

- Make decisions according to mission and plans
- Orientate ourselves toward measurable results in every endeavor
- Communicate according to a standard of "compassionate honesty"
- Work to acknowledge and understand all points of view

Who's who at the International WAGR Syndrome Association

The International WAGR Syndrome Association is governed by a volunteer Board of Directors, supported by an Executive Director, and various volunteer Coordinators and Leaders to ensure advancement of the IWSA mission, including objectives, program development and fundraising goals.

For more information on current IWSA Board members and Leadership Team, visit <http://www.wagr.org>

BECOMING A VOLUNTEER

Volunteers may apply through our application process, which is available online at <http://www.wagr.org> or by contacting a Board member or the Executive Director.

Once established, there are two ways for a new volunteer to communicate with the IWSA Leadership and with other IWSA volunteers:

- 1) **Email:** the IWSA maintains a listserv (group email) for discussion and planning of IWSA activities
- 2) **Facebook:** the IWSA maintains a private Facebook group called the IWSA Volunteers Forum

Volunteers are one of the most valuable resources at the IWSA and as such are extended the right to meaningful duties, fair treatment and full participation, and in exchange agree to perform their assigned duties to the best of their ability and remain loyal to the mission, goals and procedures of the IWSA.

PLACEMENT AND USE OF SKILLS

Volunteers will be matched to opportunities that recognize their talents, interests and availability for serving. If at any time a volunteer wishes to be reassigned or take on an additional project or role they are encouraged to discuss this with others in the IWSA Volunteer Forum.

To help keep the IWSA running smoothly, it is important that volunteers complete their tasks on schedule. If a deadline cannot be met, it is important to communicate that status in the IWSA Volunteer Forum immediately and/or to seek out another volunteer to help with those responsibilities.

MANAGEMENT OF VOLUNTEERS

Volunteers should work with the IWSA leadership to determine how they can most effectively serve. It is the responsibility of the volunteer to ask for assistance if needed and regularly report on progress to the IWSA Volunteer Forum.

If for any reason a volunteer is unable or unwilling to carry out his/her commitment of service, notify the IWSA Volunteer Forum as soon as possible.

If for any reason the International WAGR Syndrome Association feels the need to terminate relations with a volunteer for the protection of the organization, it can do so at its sole discretion.

***“Never doubt that a small group of thoughtful committed citizens can change the world. Indeed, it's the only thing that ever has.”
~ Margaret Mead***

RECOGNITION & REWARDS

The IWSA seeks to honor and recognize its volunteers from time to time and in various ways.

Volunteers shall not expect to receive any form of payment, including wages, food, clothing, shelter or other kinds of payment, for volunteer talents and services contributed to the IWSA.

The IWSA encourages volunteers to help create and encourage a culture of mutual appreciation and gratitude for the hard work and contributions of fellow volunteers and encourages all volunteers to take the time to express thanks and appreciation to others when appropriate.

LIABILITY

The International WAGR Syndrome Association is not financially or otherwise liable for injury or casualties that occur to anyone while serving as a volunteer for the IWSA. Accordingly, volunteers agree to waive any claims against, indemnify, and hold harmless the International WAGR Syndrome Association, its respective officers, directors, employees, sponsors, representatives and volunteers from any and all liability, including attorney fees, that may accrue on account of, or in any way growing out of, any and all property damage, personal injury, and/or economic loss as a result of or in any way related to or arising out of the volunteer's involvement with the International WAGR Syndrome Association.

DISCRIMINATION

The International WAGR Syndrome Association does not discriminate against any volunteer applicant because of race, national origin, ethnicity, citizenship, gender, age, marital status, creed, sexual orientation, disability, or any other characteristic protected by law.

SEXUAL HARASSMENT POLICY

The International WAGR Syndrome Association is committed to providing volunteers with an environment that is safe and productive and will not tolerate any form of sexual harassment among its volunteers. Any volunteer who has a complaint or knowledge of sexual harassment should bring it to the immediate attention of the Volunteer Forum, the Executive Director, or a member of the Board of Directors.

DISPUTE RESOLUTION

If an issue or dispute should arise between volunteers, the parties involved should first communicate directly with one another in a respectful attempt to reach a mutual understanding. If the parties cannot reach a reasonable resolution, then a volunteer can request mediation from the Executive Director or the Board of Directors.

The International WAGR Syndrome Association private Facebook group for parents and any/all public social media (including Facebook, Twitter, etc) may not be used as a medium for airing conflicts.

Conduct Guidelines: Representing the International WAGR Syndrome Association

All actions, such as speaking publicly, posting online, raising funds, and spreading awareness that are performed on behalf of the International WAGR Syndrome Association must be carried out with a positive and professional customer service approach. It is likewise the responsibility of volunteers to regularly visit the wagr.org website, read informational emails, and stay current and knowledgeable about IWSA activity and accomplishments.

Professional, respectful and timely communication is expected of everyone representing the IWSA whether in person, by email, phone or other communication form.

EMAIL POLICY

An IWSA email address (firstname.lastname@wagr.org) will be created and maintained for individuals who:

- Have an active staff or volunteer leadership role. Email accounts not used for 60 days may be deactivated and possibly deleted
- Need to send email as a representative of the IWSA
- Have signed the IWSA Code of Ethics statement; and
- Have been approved by the IWSA Board of Directors and/or Executive Director as having a role that requires an individual email account

Expectations associated with maintaining a International WAGR Syndrome Association email account include:

Emails received will be responded to in a timely manner, usually within 48 hours. An out-of-office message should be set for emails that will be unmonitored for greater lengths of time.

Although generally less formal than other written communication, email is a business communication tool and users are obliged to use it in a responsible, effective, polite and lawful manner, recognizing that you and the IWSA can be held liable for unlawful, libelous or defamatory emails.

IWSA email should not be used for personal matters, but rather for IWSA business only.

All email accounts and content maintained on our email systems are property of the International WAGR Syndrome Association.

COMMUNICATION & TRANSPARENCY

Volunteers shall recognize their work as being done as part of a larger team and therefore will keep the lines of communication open as appropriate within and among the various departments of the organization.

Communication is important both to obtain information and feedback from volunteers and to share with them new information about the IWSA. Email, Facebook, teleconferences and webinars will be used, but volunteers should feel free to share

where they see opportunities for growth, both for the organization and for themselves as volunteers.

All IWSA communication involves “compassionate honesty.” Our communications with one another shall be respectful, direct, and truthful with intent to resolve problems.

SOCIAL MEDIA POLICY

The International WAGR Syndrome Association considers social media sites (including, but not limited, to Facebook, Instagram, Twitter, Pinterest) to be an important extension of our communications strategy.

Volunteers must seek approval from the IWSA Executive Director before setting up any social media account which uses any name, logo, text, or image associated with IWSA.

Any and all such accounts are considered International WAGR Syndrome Association social media accounts for all purposes, and must adhere to the following rules:

1. All International WAGR Syndrome Association communication channels should only be used to:
 - Fundraise for the International WAGR Syndrome Association,
 - Raise awareness for the International WAGR Syndrome Association,
 - Advertise and raise support for officially-sanctioned International WAGR Syndrome Association events,
 - Share information relevant to the mission of the International WAGR Syndrome Association.

2. Volunteers cannot use IWSA social media accounts to advertise fundraising events for themselves or for organizations other than the International WAGR Syndrome Association.

3. An IWSA Board member or Team Leader or Coordinator must be a full-level administrator on any Facebook or other social media page which contains any IWSA-branded event or image.

4. Volunteers operating International WAGR Syndrome Association social media accounts can and should advertise fundraisers that directly benefit the International WAGR Syndrome Association.

5. If or when a volunteer leader of a IWSA-sanctioned event ceases to serve in that role, the volunteer should immediately remove him or herself from administrative rights of the social media page, or the IWSA will remove the volunteer upon learning of their intent to not continue with the event. At their discretion, IWSA will maintain the account until a new volunteer leader is placed in the role, or delete the account. At all times the

account remains the property of the IWSA and under no circumstances shall it be used for any purpose other than those set forth in this section.

6.The International WAGR Syndrome Association reserves the right to remove any content found objectionable on IWSA-branded social media sites.

7.Volunteers can be removed from their position on IWSA social media pages should they violate any of the communications policies outlined in this Volunteer Handbook.

Volunteers are encouraged to use their personal social media platforms to advocate for WAGR syndrome awareness, education and fundraising on behalf of the International WAGR Syndrome Association.

ONLINE or WRITTEN COMMUNICATION

All volunteers agree to communicate in writing with sensitivity, patience, and respect. Volunteers should remain conscious of the possibility for misinterpretation of tone and inference, especially in email. Volunteers agree to use clear and kind language when formulating messages.

PATIENT/FAMILY SUPPORT

Volunteers will remain sensitive to the experiences of those who contact the International WAGR Syndrome Association. Volunteers agree to become familiar with educational tools and materials that offer accurate information to patients and other individuals contacting and engaging the IWSA.

Volunteers are not permitted to offer medical advice of any kind, but can direct those in need of medical information to the IWSA Director of Research and Medical Advocacy.

USE AND COPYRIGHT OF WEBSITE

Volunteers will become familiar with the International WAGR Syndrome Association website. Using the IWSA website for personal business promotion or other advertising is not permitted.

International WAGR Syndrome Association reserves all rights and privileges to its logo, graphics, endorsement, and property, which cannot be used without express written consent of the IWSA Board of Directors, Executive Director and/or the IWSA Communications Coordinator.

CONDUCT

The following Code of Conduct agreement, which establishes an expectation of professional and respectful behavior, must be signed by volunteers working in an on-going role with the IWSA. Volunteers represent the IWSA in a highly public capacity and may be working with privileged information.

No volunteer may:

1. Authorize the use of the name, emblem, endorsement, services, or property of the International WAGR Syndrome Association for the benefit or advantage of any person or organization, except in conformance with IWSA policy.
2. Accept or seek on behalf of any person, any financial advantage or gain of other than nominal value offered as a result of the volunteer's or employee's affiliation with the International WAGR Syndrome Association, or knowingly take any action or make any statement intended to influence the conduct of the IWSA in such a way as to confer any financial benefit on any person, corporation, or entity in which the individual has a significant interest or affiliation (see IWSA Conflict of Interest policy).
3. Publicly use any International WAGR Syndrome Association affiliation in connection with the promotion of positions on any issue not in conformity with the official position of the IWSA.
4. Disclose or use any confidential IWSA information that is available solely as a result of the volunteer's affiliation with the IWSA to any person not authorized to receive such information or use to the disadvantage of the IWSA any such confidential information, without the express written authorization of the IWSA Executive Director (see Confidentiality Policy).
5. Operate or act in a manner that creates a conflict with the interests of the IWSA and any organization in which the individual has a personal, business, or financial interest. The individual shall disclose such conflict of interest to the IWSA Executive Director or to a member of the IWSA Board of Directors upon becoming aware of it. The individual will refrain from participating in any decisions or voting in connection with any matter which involves a conflict of interest (see Conflict of Interest Policy).

6. Conduct themselves in any manner deemed inappropriate by the rule and guidelines provided by the IWSA which includes, but is not limited to:

7. Theft or inappropriate removal or possession of IWSA property or that of any volunteer, agent or visitor, including failing to cooperate fully in any investigation of improper usage of IWSA property,

8. Volunteering under the influence of alcohol or illegal drugs, and/or illegal or unauthorized possession, distribution, sale, transfer, or use of alcohol or illegal drugs in the volunteer environment,

**“We can do no great things –
only small things with great love.”
~ Mother Teresa**

9. Creating a disturbance at IWSA sponsored activities or in areas which could jeopardize the safety of others, including any violation of any federal, state, or local safety or health law while acting as a volunteer of the IWSA.

Volunteers are likewise asked to certify that the statements made in their volunteer application are true and correct and have been given voluntarily. The International WAGR Syndrome Association may verify in whole or in part any information provided on the application. Information provided in the application will be kept confidential and will only be disclosed by the IWSA if under a legal obligation to do so.

CONFLICT OF INTEREST

The International WAGR Syndrome Association wants all volunteers to fully recognize the importance of their duty to IWSA constituents and supporters and the necessity to act in a manner that merits public trust and confidence. It is therefore necessary for volunteers to refrain from engaging in any transaction in which personal interests conflict, potentially conflict or appear to conflict with those of the IWSA.

An actual or potential conflict of interest occurs when a volunteer is in a position to influence a decision that may result in a personal gain for the volunteer or for a relative of that volunteer as a result of IWSA business dealings. For the purposes of this policy, a relative is a person who is related by blood or marriage, or whose relationship with the volunteer is similar to that of persons who are related by blood or

marriage. Participation in any activity prohibited by this Policy can result in termination of volunteer service.

While some conflict of interests are easily identifiable, the IWSA requests that all volunteers be aware of examples of conflict of interest to promote the best working environment for the IWSA. All public statements on behalf of the International WAGR Syndrome Association should be made by those dedicated to it in an official capacity by a designated IWSA Coordinator/Leader, the Executive Director, or a member of the IWSA Board of Directors.

The following list of “conflict of interests” is illustrative only and should not be regarded as all-inclusive:

Gifts. No volunteer shall solicit for compensation of any kind (including gifts, cash, discounts, concessions, services or other similar item or benefits) for services rendered as part of his or her volunteer service. This includes payment for speaking engagements or for participation in workshops or similar activities. NOTE: If a person or organization wishes to make a charitable donation, volunteers are encouraged to direct them to the proper donation channels, or if that is impossible, direct them to the IWSA Treasurer, Executive Director or Fundraising Coordinator so that the donation can be processed correctly.

Improper Influence: Any volunteer or relative should not, when acting on his or her own behalf or when acting on behalf of another person, business or organization, attempt to influence the IWSA position on any issue, matter or transaction nor participate in any discussions pertaining to a related organization.

Confidential Information: As explained in the Code of Conduct, inside, personal or sensitive information should not be used either for the purposes of gaining advantage for one’s self, a relative, or another organization or for any other purpose not specifically approved for use by the IWSA.

Political Activities: Volunteers are encouraged to take an active interest and to participate in the political and governmental process. However, except for those authorized to act on behalf of the IWSA concerning official affairs, volunteers participating do so as individuals and not as official representatives of the IWSA. To avoid any inference of support or sponsorship by the IWSA, a volunteer must never represent that his or her political donation, endorsement or other political activity was made or engaged in with the approval, or on behalf, of the IWSA.

CONFIDENTIALITY

Designated and authorized volunteers may be exposed to confidential information that is defined as inside, personal or sensitive information, and may include contact information, health information, or personal experience stories. The Code of Conduct signed by all volunteers upon completion of their volunteer application includes a confidentiality statement barring the sharing or disclosing of this information for any unauthorized purposes, including personal benefit.

“You may not have saved a lot of money in your life, but if you have saved a lot of heartaches for other folks, you are a pretty rich man.”
~Seth Parker

EVENT ORGANIZING GUIDELINES

*The IWSA gratefully welcomes those who wish to organize events that raise funds and awareness on behalf of the International WAGR Syndrome Association, in accordance with our mission. **Please review these guidelines if you are interested in hosting a special event or fundraising for the IWSA.***

It is our goal to empower, not limit, you in your desire to help this cause. Please use this information as a tool that leads you to a successful and rewarding experience on behalf of the International WAGR Syndrome Association. If at any time you have questions or need more guidance, please contact the IWSA Executive Director or Fundraising Coordinator directly or at reachingout@wagr.org.

PLANNING YOUR EVENT

Because of the International WAGR Syndrome Association's status as a nonprofit organization and the nature of its mission, most volunteers will in some way be a part of the fundraising process. Fundraising activities bring about significant tax, accounting, and liability issues and income must be documented according to state and federal requirements in order to prevent penalty to the IWSA.

It is crucial that our volunteers are aware of proper procedures when dealing with fundraising and for this reason we have included a few funding guidelines:

- Events and promotions must fit the IWSA mission and provide a favorable, non-controversial public image.
- The International WAGR Syndrome Association name or logo can only be used with prior approval. Materials printed with the International WAGR Syndrome Association name or logo, including letters, tickets, ads, banners, etc. that promote an event, or request contributions, need to be reviewed by the IWSA Communications Director and/or Volunteer Forum,.
- Federal tax laws disallow third-party events from using the International WAGR Syndrome Association sales tax- exemption number or Federal Employer Identification Numbers when purchasing any goods or services from suppliers/vendors.
- Bank accounts cannot be opened in the name of the International WAGR Syndrome Association for any reason.

EVENT LIABILITY

The volunteer organizer is responsible for filing for any necessary permits or insurance coverage needed to hold the local third-party fundraising event. The International WAGR Syndrome Association cannot promise to pay or reimburse fees for such permits or coverage.

The International WAGR Syndrome Association cannot be held responsible in any way for casualties, thefts or accidents that occur at the event.

The International WAGR Syndrome Association is not financially or otherwise liable for the promotion or staging of local events or projects. This includes ticket sales or other administrative aspects. The organizer must seek sponsorship, or have the means to cover up-front costs, such as ticket sales, promotion costs, or supplies.

FINANCES

As a responsible steward of public funds, the International WAGR Syndrome Association expects that a reasonable percentage of the gross revenues from fundraising events be directed to the IWSA. The total cost to produce the event should not exceed the amount generated from the event. If event expenses are greater than the total collected, it is the organizer's responsibility to cover the additional expense.

The public should be informed of any net amounts that will actually be donated to the International WAGR Syndrome Association. Potential donors must be informed that only portions of proceeds will be donated whenever less than 100% of the net income will be donated. The organizer is responsible for accounting documentation of revenues and expenses.

All proceeds must be mailed to the International WAGR Syndrome Association (PO Box 769, Hanover, PA, 17331) no later than 21 days following your event. Expenses for which reimbursement is sought must be pre-approved by the IWSA Executive Director, Volunteer Forum and/or Fundraising Coordinator, then submitted with accurate receipts. Expense reimbursements will be provided by the IWSA within 30 days following submission of receipts.

The International WAGR Syndrome Association should be informed, in advance, of any companies approached for underwriting or contributions for the event. No volunteer can take a commission for hosting an event.

SPONSORSHIPS

If you plan to seek sponsorships and/or provide benefits to a business for their sponsorship, please contact the IWSA Executive Director and/or Fundraising Coordinator for additional guidance and instruction.

RECEIPTING AND TAX-DEDUCTIBILITY OF CHARITABLE DONATIONS TO 501(C)(3) ORGANIZATIONS

Receipts must be distributed with accurate information, and income needs to be documented according to state and federal requirements and the nature of the donation in order to prevent penalty to the International WAGR Syndrome Association. All donations or event registrations are accepted by checks made payable directly to the IWSA or directly through the IWSA website by credit card or Paypal.

Donation of Services & Products

If goods and/or services are received in return for charitable donations (i.e. auction purchases, tokens of appreciation, giveaways, meals, beverages, etc.) the fair market value of those goods and/or services must be determined by the donor, in writing, and provided to the IWSA for documentation.

Purchase of Donated Services & Products

Supporters making a purchase of an item through a silent auction, live auction, raffle, etc., should contact their tax accountant to determine what, if anything, will be deducted from the total purchase amount to determine the tax-deductible portion of the donation. (i.e. if event fee is \$100, but \$50 covers meal cost owed to hosting facility, only \$50 remains as the tax deductible donation to the charity).

Receipts for Charitable Donations

The IWSA policy is to make every effort to acknowledge all donors with an official receipt outlining the tax-deductible portion of that donation. A credit card transaction receipt is emailed directly for all donations made online to the IWSA.

All donations over \$25 and received in the mail by check will have a receipt mailed to the name appearing on the check received and that individual, corporation, IWSA, etc. will be the eligible party for tax benefits received as a result of the donation.

Cash donations should be converted to a cashier's check and subsequently donated in a single sum to the IWSA. Donors contributing in cash should be made aware that their gift will *not* be acknowledged as a tax-deductible donation to the IWSA. If the donor of cash, property or in-kind donations wishes to receive tax documentation, the organizer must provide the detailed information listed below:

- Donor's complete name and address
- Date and amount of the contribution
- Whether the contribution was cash, in-kind services or property (non-cash)
- If applicable, description of the type of property and a good faith estimate of the fair market value
- If applicable, detailed description of any goods and services provided in exchange for the contribution

IWSA Board members, Executive Director and/or Fundraising Coordinator are available to offer general advice on event or project planning along with tips for your specific type of event, implementing income documentation procedures, as well as having educational and awareness materials provided for your event, if appropriate.

Please contact the IWSA at reachingout@wagr.org to have announcements about your event posted on the IWSA website, IWSA Facebook pages and/or on other social media outlets.

International WAGR Syndrome Association Volunteer CODE OF CONDUCT

I understand and agree that submitting a volunteer application form does not automatically register me as a International WAGR Syndrome Association volunteer, and that there may be certain qualifications I must meet, including the acceptance of the following established volunteer policies and procedures before I may begin volunteering:

I desire to serve as a volunteer with the International WAGR Syndrome Association (the "IWSA") and help further its stated mission.

As a volunteer, I understand that I may be exposed to confidential information that is defined as inside, personal or sensitive information, and may include contact information, health information, or personal experience stories. By agreeing to this Code of Conduct, I am prohibited from sharing or disclosing this information for any unauthorized purpose, including personal benefit.

In all situations in which the IWSA is involved, I promise to conduct myself according to the standards set forth in the International WAGR Syndrome Association Volunteer Handbook, including the IWSA Code of Ethics and the IWSA Conflict Resolution Policy, and I understand that it is my responsibility as a volunteer to remain professional, respectful and discreet at all times.

I acknowledge that I have access to and understand the contents of the Volunteer Handbook. I have now, and in the future, the opportunity to ask and receive answers to any questions I have about the contents of the Volunteer Handbook.

I also understand that I must disclose any of my outside interests that may be in conflict or competition with the interests of the IWSA or that stand to benefit from my involvement therewith, and then refrain from participating in any discussions pertaining to those conflicts.

I understand that the IWSA is not financially or otherwise liable for injury or casualties that occur to anyone while serving as a volunteer for the IWSA.

I hereby grant the IWSA specific permission to reproduce, publish, circulate, copyright, or otherwise use any and all photographs and/ or videotape of me and/or my family taken at any volunteer event, for use by the IWSA.

CODE OF CONDUCT CERTIFICATION AND DISCLOSURE

By signing this form or selecting the "I agree" (check box), I certify that:

- I have read and understand the IWSA Volunteer Code of Conduct and I agree to comply with the terms therein, as well as applicable laws that impact the IWSA.
- I also understand that should I not maintain the conduct outlined above, the IWSA reserves the right to terminate my voluntary position immediately. I also have the right to step down from my volunteer position at any time.

I Agree

Signed _____

Date _____