

WSA VOLUNTEER HANDBOOK



Updated 2022



willamssyndrome
ASSOCIATION

Dear Friends,

You may be reading this manual as a preface for hosting or helping at an event, or program. Perhaps you plan to host or help with a fundraiser, or help families connect. Or maybe you are simply looking for more information about what we do at the Williams Syndrome Association... Whatever the reason, **Thank you!**

Thank you for taking an interest in our organization, and for considering the impact you can have on countless individuals with Williams syndrome. Each year, hundreds of individuals like you, individuals of all ages and in all life stages help us make a difference for those with WS, and we cannot thank you enough. You will see your impact in the smiles you will see on the faces of those you support. You will feel your impact in the hugs and high fives you will receive from individuals with Williams syndrome, and you will hear about your impact in the many voices raised to say "Thank you".

Lily Tomlin once said, "I always wondered why somebody didn't do something about that. Then I realized I was somebody." And Sherry Anderson noted, "Volunteers don't get paid, not because they're worthless, but because they're priceless."

The Williams Syndrome Association has been providing support and resources to families throughout the US and in many countries around the world for nearly 40 years. We are a small non-profit, made mighty by the many volunteers who help us. Volunteers are truly the lifeblood of the WSA, and we can't thank you enough for joining our vast community of priceless volunteers who are truly making a difference in the lives of individuals with Williams syndrome, and their families and care providers.

With deep appreciation,

A handwritten signature in blue ink, appearing to read "Terry", with a stylized flourish at the end.

Terry Monkaba, Executive Director

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ABOUT THE WSA

The Williams Syndrome Association (WSA) was formed in 1982 by, and for, families of individuals with Williams syndrome to provide the resources and referrals needed now, and a strong and supportive community for a lifetime.

The WSA is a 501(c)(3) nonprofit corporation, Tax ID: 22-3305007.

Our Mission

The Williams Syndrome Association (WSA) works hard to advance the interests of all individuals with Williams syndrome throughout their lifespan by providing programming and resources, supporting research, promoting partnerships and connections, and ensuring that the infrastructure of the organization has the capacity to lead our community toward its goals.

We support our mission by:

- Providing information and emotional support to individuals with characteristics of Williams syndrome, their families, and the professionals who work with them
- Developing programs and services to help build strengths and meet challenges from early childhood through adulthood
- Increasing public awareness and understanding of Williams syndrome, and
- Encouraging and supporting research into a wide range of issues related to Williams syndrome

Our Vision

We want to help ensure that all individuals with Williams syndrome have the support they need throughout their lifespan to live healthy, self-directed, productive, and meaningful lives. We believe that in order to achieve this vision, individuals with Williams syndrome must be fully included in educational, work, and community settings.

Active involvement with the WSA community provides vital, day-to-day support. The WSA has a small paid staff and hundreds of volunteers who help us organize events and support families in communities nationwide. We are parents, caregivers, and relatives of people with Williams syndrome as well as the professionals who work with them. We know first-hand the challenges of raising and caring for an individual living with the challenges of Williams syndrome. No matter the age or stage of your family member with WS, you are not alone. The WSA offers support and will help you navigate the challenges from diagnosis through adulthood.

Board of Trustees

The Williams Syndrome Association is governed by a volunteer Board of Trustees. Trustees are elected by the membership for three year terms, and may seek re-election to one additional term. The Board provides organizational oversight and works closely with staff and volunteers to establish the vision and carry out the mission of the WSA. Visit williams-syndrome.org/board to learn more about our current Board of Trustees.

Staff

The WSA has a small paid staff to handle the administrative and programmatic duties that keep our organization running smoothly. They are assisted by hundreds of volunteers who help organize events and support families in many different ways, and in communities nationwide. To learn more about the structure and administration of the Williams Syndrome Association, visit williams-syndrome.org/administration.

Diversity & Equity

It is the policy of the Williams Syndrome Association not to discriminate against any volunteer or potential volunteer because of age, race, color, creed, religion, sex, sexual orientation, disability, or national origin.

Discrimination and racism go against our deeply-held values of inclusion and equity. During the 35+ years of the life of the WSA, much of what we know has come from listening to our community and learning from individuals from the diverse population of those with Williams syndrome. Our community has both inspired and enabled us to become strong and to advocate with our families of color. Now more than ever, we dedicate ourselves to listening, learning, and supporting our diverse community. We stand with our families and friends of color and we are proud to add our voice and advocacy to express the importance of standing up for racial equality and justice.

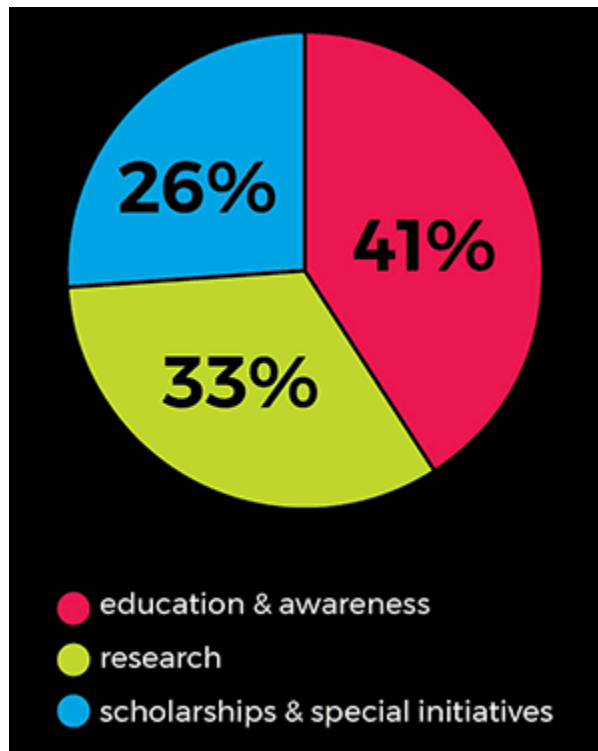
Programs & Campaigns

The WSA develops programs in accordance with its mission to provide support to all individuals with Williams syndrome and their families for a lifetime. Specialized educational and enrichment programs and resources, as well as recommendations for, and access to, additional important resources and agencies, scholarships for non-WSA programs, financial aid for travel and lodging associated with critical medical and surgical procedures, research funding and important partnerships combine to help ensure that individuals with WS have the best opportunity for healthy and happy lives. Visit williams-syndrome.org/programs to learn more about these invaluable programs.

Community Donations At Work

The Williams Syndrome Association takes pride in the comprehensive stewardship of every dollar raised, and our ability to consistently provide more than 85 cents of every dollar to programs and support. We prioritize funding into three major categories:

- Education and Awareness resources and programs provide assistance and training to families, caregivers, educators, and community members which promote meaningful inclusion across all environments, increase community and membership knowledge of Williams syndrome, and ensure individuals with WS reach their full potential.
- Research is integral to understanding Williams Syndrome and uncovering new discoveries to help inform effective therapies. Maintaining partnerships through the medical advisory board and facilitating collaborative opportunities throughout the medical community allows for the WSA to fund high impact research.
- Scholarships provide financial assistance to families and children who want to attend camps throughout the nation, the national convention or other programs facilitated by the WSA, or post-high school programming of any type. Scholarships help to ensure that all families, from all backgrounds, can be included in the programs they need, regardless of their financial position.



VOLUNTEER GUIDELINES

Becoming a Volunteer

There are a number of ways to volunteer with the WSA – hosting events or fundraisers, joining the Board of Trustees, volunteering in our Family Support Network, helping at camps, conventions or Adventure Seeker trips... the list is lengthy. Regardless of the level of help you can provide, we value your partnership and dedication both to our organization and the families we support.



Becoming a volunteer with the WSA signifies a partnership, and like all successful partnerships it is based on mutual respect and a common goal – *staff and volunteers work together* to ensure that the WSA mission is fulfilled in the best way possible and individuals with Williams syndrome and their families have the support and resources they need throughout the lifespan. As members of *Team WSA*, we want every volunteer to have a positive and rewarding experience from start to finish. You will receive training when needed to perform the task at hand, all the support required during the task or event, and follow-up opportunities. From committee meetings, to events, and follow-up, our goal is to provide an atmosphere of collaboration that is free of conflict, and honors all participants. Working together, we can accomplish a lot – and have a great time in the process!

Volunteer Policies

Confidentiality

The WSA recognizes the importance of confidentiality. Therefore, the organization will respect the privacy of personal information of those it serves or employs. You are responsible for maintaining confidentiality of all information to which you are exposed while serving as a volunteer, whether this information involves staff members, volunteers, clients, or other people, or involves overall program or association business.

Drug-Free Policy

The WSA strictly prohibits the use, sale, dispensing, possession, or manufacture of illegal drugs in the workplace, as a volunteer or while engaged in WSA activities.

Dress Code

As a volunteer, you are responsible for presenting a positive image to clients and to the community as a representative of the WSA. You should dress appropriately for the conditions, performance, and family-friendly nature of your duty.

Fiduciary Responsibility

When someone contributes during a WSA fundraising event, their understanding is that the money they give will go directly to the organization. When fundraising on behalf of the WSA, it is your obligation to ensure all of the money raised is provided to the WSA. *Approved expenses incurred while fundraising will be reimbursed after the donated funds have been submitted.* This process is covered in the [Expense Guidelines](#) section of this manual.

Harassment

The WSA is committed to a work environment that is professional and harassment-free for all employees and volunteers. Harassment includes, without limitations, verbal, physical, visual, and innuendo. It also includes unwelcome sexual advances, requests for sexual favors, sexually motivated physical contact and other verbal or physical conduct, or visual forms of harassment of a sexual nature when submission to such conduct is either explicitly or implicitly made a term or condition of employment or is used as the basis for unreasonably interfering with an individual's work performance or creating an intimidating, hostile, or offensive work environment for employees and volunteers.

People-First Language

People First Language is a way of communicating that reflects knowledge and respect for people with disabilities by choosing words that recognize the person first and foremost as the primary reference and not his or her disability. People First Language puts the person before the disability, and describes what the person has, not who the person is - eliminating old, prejudicial, and hurtful descriptors. People First Language is not political correctness; instead, it demonstrates respect and the Golden Rule. It can change the way we see a person, and it can change the way a person sees themselves. Here are a few examples:

- Say "people with disabilities", not "the handicapped or disabled".
- Say "Kate has Williams syndrome" not "She's WS".
- Say "people with Williams syndrome" not "WS people"

Status within the Organization

As a volunteer for the WSA, you cannot claim to be an employee of the organization in any capacity, or for any purpose.

Weapons

It is the policy of the WSA that no unauthorized firearms or weapons are permitted at WSA-sanctioned events. This includes, but is not limited to, tear gas dispensers (or similar disabling devices), guns, starting pistols, flare pistols, pocket or hunting knives with a blade exceeding three inches in length, or other objects that are intended for use as a weapon.

Media

If any media outlet contacts you for information or an interview about the WSA, please refer them to the Executive Director. If a media representative approaches you to share your opinions on a WSA matter while at a WSA event, please refrain from answering questions.

Background Checks

If your involvement as a volunteer includes direct contact with unchaperoned individuals with WS (of any age) or the handling of money or other financial transactions on behalf of the WSA, a background check will be required.

Though this very rarely occurs, if indiscretions in any of the areas above are noted, that person will immediately be removed from the activity and any future volunteerism with the WSA. Examples of indiscretions include: gross misconduct or insubordination, being under the influence of alcohol or drugs, mishandling of organizational funds, theft of property or misuse of equipment or materials, or abuse or mistreatment of members, guests, or other volunteers.

Williams Syndrome Association Volunteer Agreement

This is to acknowledge that I have received, read, and agree to comply with the Volunteer Guidelines and Policies contained in the Williams Syndrome Association Volunteer Handbook. I understand that my involvement as a volunteer includes direct contact with unchaperoned individuals with Williams syndrome (of any age) or the handling of money or other financial transactions on behalf of the Williams Syndrome Association, and therefore a background check is required. I also understand that this handbook is not a contract of employment and that no express or implied promise or guarantee with regard to the duration or terms of volunteering is contained in the Volunteer Handbook.

Name

Signature

Date



WAYS TO VOLUNTEER

The Williams Syndrome Association is a small organization with a big mission. With only a handful of staff members, we rely heavily on our powerful network of volunteers. With your help, we can enrich the lives of more individuals with Williams syndrome, raise awareness, host more events and so much more.

There are numerous opportunities for volunteerism within the WSA. Whether you prefer to donate your time to host a social or educational event, help with childcare and programs during a convention, or create a fundraiser to support the WSA, your support is invaluable!



Join Us!

Programs

Convention

The WSA sponsors a [national convention](#) every two years. The convention is held at varying locations around the country and includes an exhibit fair, general sessions, daily workshops, child care and excursions for children, special programs for teens and adults, opportunities to participate in ongoing research, and evening programs.

Eight separate programs are run throughout the convention week – one providing 60+ educational program options for parents, and seven additional programs for individuals with Williams syndrome and their siblings. The special programs for individuals with WS provide a vacation-like experience with their peers – many of whom have never met another child with WS, or have only met a few. It takes more than 150 volunteers to support these programs. With your help, parents can attend sessions, secure in the fact that their kids are safe and having a great time!

Family Support Network

The WSA's Family Support network is a nationwide network of WSA members (parents/relatives/caregivers/professionals) who want to connect, and help others connect with "communities within our community". Communities may be based on simple demographics such as age or gender of son/daughter with WS or ethnicity, geography, developmental and life stages, medical, emotional or educational issues and more -- all under the broad premise of "See a need, Fill a need." Volunteers with a special expertise/interest in various groups are needed to help facilitate calls and lead discussions.

The Williams Syndrome Association is organized into 19 regions across the United States. Each region works to provide resource information and social and educational opportunities to its members. Volunteers (parents and grandparents who can provide resources and information) have been identified in each state to help provide personal information and support. These Family Support Network volunteers are joined by many others who work hard to facilitate annual gatherings such as picnics, conferences, and fundraising events.

There are two types of Family Support Network volunteers:

- Family Support Specialist: Volunteers who support local families in multiple ways, including being the first point of contact locally when a family receives a diagnosis or moves into the area, providing information about local resources, and hosting social events for local families.
- Family Support Volunteer: Anyone who volunteers to support other families, either locally or virtually, in a specific way, which could include connecting with other families, leading a networking group on Zoom, or hosting an occasional social event, for example.

If you're interested in volunteering in our Family Support Network, contact the national office or email familysupport@williams-syndrome.org.

Local Area Social Events

One of the best ways to connect with other families and people with Williams syndrome, who can provide lifelong friendship and support, is to attend an event. The WSA, with the help of volunteers across the country, plans many events throughout the year.

Social events are varied - from family picnics, to gatherings at the zoo, playdates, mom's brunches, bowling, holiday parties or other fun activities that bring local families together. You can also be creative and host events that allow people to gather virtually, or more "on the go".



Traditional Social Events

Family Picnic - Picnics can be held in a park or your backyard. Wherever you chose, make sure there are bathroom facilities. Ask families to bring their own picnic or bring a dish to share, plus blankets or chairs. Make sure to have activities for the children, a playground, lawn games, bubbles, etc.

Family Gatherings at Local Venues - These can take place at a zoo, aquarium, museum, or anywhere in your area. Families purchase their own tickets (through the WSA website). A time is set for families to meet at the venue and to enjoy visiting the exhibit together.

Mom's Brunch/ Playdates/ Coffee & Conversation - Typically held in someone's home. A time for moms (dads, grandparents, etc) to socialize and share. Ask each attendee to bring a dish to share.

Bowling - Pick a date and time, and enjoy bowling a game or two. WSA will help with contract and group rates. Set up a group meal/snack or have everyone purchase their own.

Holiday Party - Use the holiday or season as the party theme. Holiday parties can be held at home or at a venue. Either ask families to bring a dish to pass or include the cost of food as part of the registration fee. Games and decorations can revolve around the theme.

On-the-Go or Virtual Events

These events are perfect when it's not easy to get everyone together in one place at the same time, or when it's better to have families gather in their own group (perhaps socially distanced), rather than all together. In addition to the list below, consider an adventure day at a zoo or park, a golf outing, an outdoor concert or an outdoor variety show.

Road Rally - A Road Rally is basically a large-scale scavenger hunt. Teams drive around following a set of instructions and find the answers to a set of clues and questions. Throughout the route, teams may be required to complete other tasks as well. Planning a Road Rally (Car Rally) is a great way to have fun! It could also be used as a fundraiser. Check out this [tip sheet](#) to learn more.

Sidewalk Chalk - A great family activity! Everyone brings their own chalk, or you can supply a bucket of chalk for each group. Start by portioning off squares for each group (6 feet apart if adhering to social distance guidelines) and ask each group to design and color their space. This can be done in your driveway, your front walk, or in a parking lot you reserve. You can make it a friendly competition or use a theme.



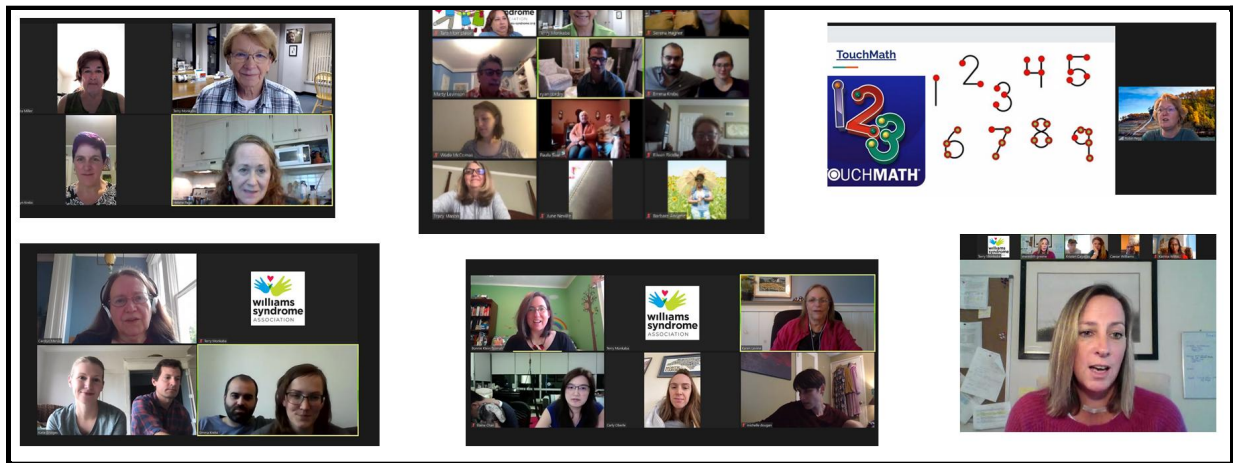
Scavenger Hunt - Creating a casual scavenger hunt is another fun outdoor activity. Make a list of things in and around your neighborhood or town for everyone to find - from a plastic flamingo to a bright yellow front door. Be creative! Pick a theme such as finding green items or shamrocks for St. Patrick's Day or flowers of a certain color in the spring. Split up into small groups, for friendly competition (another great "socially distanced" activity). Consider providing prizes to the first and second teams to find everything on the list. Other ideas for! Check out these [tips](#). This could also be a fun fundraiser.

Movie Night - There are several ways to host a movie night. For a smaller group, you can set up in your own yard. All you need is a surface on which to project the movie, an LCD projector and speakers. And a movie, of course! Be sure to consider seating when planning. If you are practicing social distancing, be sure there is enough room to allow for 6 feet between each group. Everyone can sit on blankets or chairs and bring their own



snacks. For a larger group, the first thing to consider is location. Are you able to rent an area, do you own property with a field, can you rent out a parking lot? Where will the movie be projected? Will you have a screen, or use the side of a building? You can even make it a drive-in! There are companies that set up the projector and screen for a movie night for a fee. Check out these tips on [how to host a movie night](#).

Virtual Event - A virtual event is any organized meet-up that takes place online rather than in a physical location. Virtual event activities may include a meet and greet, show and tell, dance party, scavenger hunt, music class, story time or an educational event. If you have an idea for a virtual event, contact the WSA office. The WSA office can help coordinate your virtual gathering by providing a Zoom link and creating an event registration page.



Fundraisers

WSA members can help individuals with Williams syndrome by holding fundraisers in support of the WSA. WSA volunteers/families host walks across the country during the month of May, and a variety of other events throughout the year to raise funds for programming, research, and scholarships. The national office is standing by and ready to help in a number of different ways to suit your event.



There are three ways to host WSA fundraisers:

- **Third-Party Independent Fundraisers:** a business, organization, community group, school or individual plans and hosts a program or an event to benefit the Williams Syndrome Association. It is planned and executed independently of the WSA. WSA staff will help to promote the event to our community members in the location of the event. Donations and fees provided for this type of fundraiser are not paid directly to the WSA, and therefore not tax deductible.
- **WSA Co-Hosted Fundraisers:** The WSA provides administrative support with registration page, flyers, WSA printed materials, videos, slide presentations, fact sheets, coloring pages, an item for raffles/giveaways, etc. Donations and event-related fees collected by the WSA are tax deductible in accordance with federal guidelines.
- **Galas and Large-Scale Fundraising Events:** The WSA partners with a business, organization, community group, school, or individual to plan and host a program or event to benefit WSA. It is planned in collaboration with the WSA and the WSA staff and organized in accordance with parameters and guidelines related to budget, audit requirements, and expense to income ratios. Donations and event-related fees collected by the WSA are tax deductible in accordance with federal guidelines.

Families across the country raise hundreds of thousands of dollars through a wide variety of events annually. See below for information on many different types of events.

Examples of Fundraisers

Dine/Shop to Donate - Many chain restaurants/storefronts offer “dine/shop to donate” fundraising options. You choose a date and invite your friends/contacts to eat/shop onsite. The restaurant then donates a percentage of the evening's proceeds to the WSA. It works for dinner, breakfast or lunch. In addition to chain restaurants, many coffee shops, bakeries, ice cream shops and local “mom and pop” restaurants will agree to do something similar. All you need to do is ask! Either give them a call or stop in and ask to speak with the manager.

Bake Sale - A bake sale is a great fit for anyone, including kids and teens! You can hold a bake sale in your driveway, work with your child's school or host a bake sale at your church, school, gym, or community center. Regardless of the location, it's easy to plan. All you need to do is recruit some bakers to contribute yummy items to sell and then gather volunteers to help you sell the items. After the sale, you can send one check for the total to the WSA.

“In Home” Sales - These days, there are so many people involved with companies such as Pampered Chef, Mary Kay, etc. If you know someone, ask them to participate in Awareness Month (or anytime!) by donating a portion of the proceeds from a private party to the WSA. All you do is invite your friends and the salesperson will tell them all about the line of items. After a fun evening, you will all have some great new purchases and will have raised money for the WSA!

Jean Day/Hat Day - Many offices and schools offer an opportunity for their employees/students to modify the dress code for a day. Offices often allow a Jeans Day and schools are known to support Hat Days. The understanding is that they make a donation to a specified charity for the privilege. Why not make it a WSA fundraiser? Work with your HR department or school staff and ask if it would be a possibility.



Dance-a-Thon - A dance-a-thon fundraiser is great fun! It can be a simple dance party event that raises funds from tickets, raffles, and concessions, or it can be a marathon event that requires participants to build teams, collect pledges and sponsors based on the numbers of hours danced in the time frame given. Either way, your guests are guaranteed to enjoy!

Virtual Bingo - Virtual bingo games are a great way to have fun with friends and family. They are relatively easy to plan, there is little overhead, and friends of any age can play. More importantly, you don't need to leave the house and can simulate all the joys of a bingo hall over a live connection. This [planning guide](#) makes hosting virtual bingo easy and fun!

Golf Tournament - People are drawn to golf tournaments because they provide an opportunity to enjoy a day of leisure in a social atmosphere. The golf course is recognized as a great place for developing strong friendships and working relationships while having fun, and raising funds. Check out this [quick reference guide](#) to learn more.

Road Rally - A Road Rally is basically a large-scale scavenger hunt. Teams drive around following a set of instructions and find the answers to a set of clues and questions. Throughout the route, teams may be required to complete other tasks as well. Planning a Road Rally (Car Rally) is a great way to have fun! It could also be used as an [on-the-go social event](#). Check out this [tip sheet](#) to learn more.

Scavenger Hunt - Creating a casual scavenger hunt is another fun outdoor activity. From a plastic flamingo to a bright yellow front door, make a list of things in and around your neighborhood or town for everyone to find. Split up into small groups, so everyone can keep their distance. Give out prizes to the first and second teams to find everything on the list. Other ideas for a scavenger hunt could include a theme. Finding green items or shamrocks for St. Patrick's Day or flowers of a certain color in the spring. Be creative! Check out these [tips](#). This could also be a fun fundraiser.

Examples of Large Scale Fundraising Events

- Golf tournaments
- Galas
- Walk/run (see [Step-By-Step Guide to Walks](#))
- Softball tournaments
- Carnivals



Awareness Initiatives

Williams syndrome is rare. In general, people who are not affected personally or don't have a family member or friend who has been affected know little or nothing about it. We need to change that. It is only through awareness that we can attract the research interest and funding support that is needed to solve the many unanswered questions we all have. May is "officially" Williams syndrome awareness month, but we work to raise awareness of Williams syndrome 365 days each year...and you can help.



The main goal of Williams Syndrome Awareness Month is to inform the general public about Williams syndrome. Getting the word out will assist us in helping individuals with WS and their families by educating our communities about the abilities of this diverse group. Here are a few examples of how you can participate in Awareness Month.

Contact Your City Council/Mayor/Congressman - Work to get WS on your local government's mind. Ask them to issue a [proclamation](#), declaring May Williams Syndrome Awareness Month and recognizing the great work of local volunteers and the national Williams Syndrome Association. We'll provide you with a printable informational packet to present to your government representatives in support of your request, or use this [sample proclamation wording document](#) to submit your request to your state online.

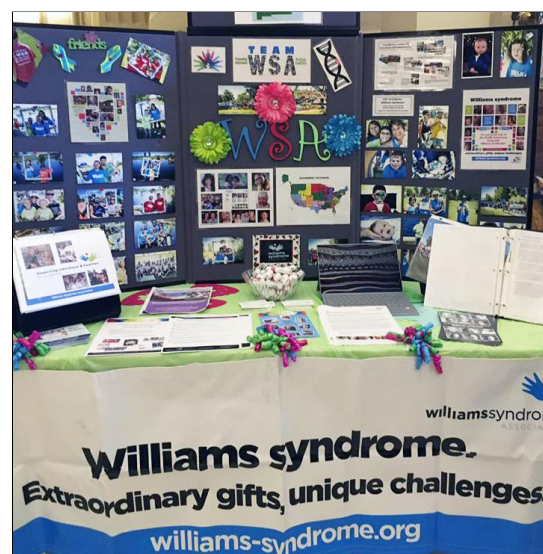
Library/School Displays - Perfect for those with a knack for the creative! Displays can be set up in showcases or on bulletin boards at local libraries, churches and/or community centers to help spread the word about Williams syndrome. You will want to approach centers as early in the year as possible to tell them about Williams Syndrome Awareness Month and reserve a time for your display. Display times during May are preferable, but if that time frame is not available, any time is a great time to raise awareness of Williams syndrome! If it's possible to get a time in April, it will also provide a time & place for you to advertise any awareness month events that may be taking place in your area. You might want to consider the following for your display: photos of individuals with Williams syndrome and of local events, information about Williams syndrome and the WSA, illustrations or something 3D to demonstrate the WS deletion, WSA materials, etc. The national office has resources to help you put together a great display.

Class Presentations - Many parents and individuals with Williams syndrome take time during awareness week to share their story and educate classes (or work colleagues) about Williams syndrome. Whether you prepare a comprehensive presentation or simply ask your child's teacher for a few moments to tell students about Williams syndrome, you'll be making a difference and raising awareness! The WSA will be happy to provide you with facts and figures for the more detailed presentations.

A Word About Williams? "What is Williams?" is an awareness initiative that anyone can take on, including children and adults with Williams syndrome. We provide cards explaining Williams syndrome and the WSA. The cards are available in language appropriate for the age of your audience, and you can even personalize your request by placing your child's photo on the card. It's a great way to share your personal journey with Williams syndrome, and if interested, you can suggest donations to support the WSA.

These are just a few possibilities! Check out our website for more [ways to get involved](#) in Awareness Month. Don't hesitate to get creative and think beyond the ideas listed above. If you have questions or want to discuss your ideas with someone, don't hesitate to [contact the WSA](#).

Another important goal during awareness month is to raise the necessary funds to support the continuing work of the WSA. The WSA relies almost entirely on fundraising to support programs and operations. Funding raised during awareness month and throughout the year increases our ability to update current programs and develop new opportunities, programs, and resources for those with Williams syndrome and their families. Walks are the primary form of fundraising held during Awareness Month. Check out the [Step-By-Step Guide to Walks](#) for more information.



GENERAL PROCEDURES FOR ALL EVENTS

Whichever type of social event or fundraiser you choose, the WSA office is available throughout the process to answer any questions, offer guidance and support you in hosting a successful event. Don't hesitate to [contact the national office](#) if you have questions or need any support.

The WSA will provide administrative support with things such as creating a registration page and informational flyer for the event, distributing flyers to members in your area, posting the event on the WSA website, and appropriate Facebook pages, sending an email blast to the mailing list, and providing you with a Zoom link if your event is virtual

Event Planning Resources

You will be provided with a web link to event support materials. Depending on the size and type of event you are hosting, you may only need one or two of the resources, but whatever you plan to do - from sending out flyers, to establishing budgets or requesting sponsorships and/or donations for raffles, the resource you are looking for will be available at this link or directly from the national office.

Here are some of the items you'll receive as [resources](#):

- Sample budget
- Solicitation letter for in-kind services
- WS/WSA messaging flyer
- Walk donation forms
- Credit Card Forms
- 501(c)(3) Letter
- Informational brochures
- Expense Pre-approval form
- Reimbursement form
- Wg
- Certificate of Insurance
- Logo Usage Form
- Communications Forms



Event Flyer

The WSA will create a flyer specific to your event. Once completed, the flyer will be shared with you for revisions, corrections and approval. We will add your event registration link (if applicable) and return to you for your use. The flyer is a great tool for marketing and publicizing your event. The only event flyers not created by the WSA would be one created by a third party (restaurants or retailers, for example.)

The WSA will distribute your flyer in a number of ways:

- We will post your flyer on the main WSA Facebook and applicable WSA Facebook network groups.
- The flyer will be posted on the WSA website on the event calendar.
- Approximately 6 - 8 weeks prior to the event, the WSA will distribute the flyer to everyone in your area.
- For walks, a reminder will be sent prior to the shirt cut off registration deadline.

Online Registration and Donation Pages

The WSA will make registration and donations easy. Our office will create online registration and donation pages with easy step by step instructions. As the event coordinator, you will receive a private link to view all activity associated with your registration, including number of participants, donations, and additional details as required.

General Event Guidelines

Finding a venue

Different events call for different types and sizes of venues. There's no right or wrong location when you're planning an event - get creative! Events are held in homes, backyards, parks, church halls, corporate meeting spaces, zoos, farms, museums, etc.

Consider the following factors when you choose your site:

- How many people do you expect to attend? This will determine the venue size.
- Who do you (or your connections) know that might have a space available (at little to no cost when possible)?
- Is the area safe? Look at proximity to busy streets, open bodies of water.
- Is there adequate parking not far from the site?
- Are there rental fees associated with the location?
- Are there adequate facilities including restrooms, shade, seating, concessions and electrical power? If not, can you augment appropriately?
- If in a neighborhood, are they amenable to having a large event?

Walk Specific:

- The location of a walk should lend itself to setting up a route to allow for people to walk varying distances.
- For kids, an ideal route length is ½ mile; for adults and families one to three miles.
- Reach an agreement between your committee and the individual who controls the site on the date and exact location, and if necessary, obtain written permission.

Building Committees & Finding Volunteers

Don't do it alone! Your friends and family have probably been waiting for a chance to get involved and to help out. Ideally, your committee will consist of local WSA families and friends, plus family members. Whether you ask other WSA families to join your committee or you reach out to friends, family, coworkers and neighbors, you will want to recruit volunteers for larger events and fundraisers. This will not only divide the workload, but will also generate more excitement about your event and introduce people to the Williams Syndrome Association and the good work that we do. The size of the committee is up to you, but remember that the more help you have, the easier and more fun it will be. Don't be afraid to ask! Share the details and let your volunteers know what you will need from them before they join the committee. With a clear understanding of their role on the committee, everyone can work together to make your event a success.

Tasks for pre-event volunteers and committee members might include:

- Solicit sponsors
- Solicit In-Kind donations (water, food, etc.)
- Ask local businesses to post your flyer
- Community Outreach (Local papers, community calendars)
- Recruit participants (if a walk or similar event) from places like churches, book clubs, girl/boy scout troops, community sports teams, etc.
- Activity Planning Committee (face painting, games, refreshments, entertainment)
- Silent Auction and/or Raffle Committee (get donations for silent auction and/or raffle)

On the day of the event you will need many hands:

- Set-up
- Registration and Check-in
- Walk Course Volunteers (to make sure the registrants stay on the correct route)
- Refreshment Station
- Greeters (direct people to registration, bathrooms and refreshments and answer questions along the way)
- Walk Leaders and Walk Sweepers (managing the end of the line of walkers)
- Raffle Tickets
- Silent Auction
- Clean-up

Great resources for volunteers:

- Churches, synagogues, mosques etc.
- Boy/Girl Scout Troops
- Cheerleading/Dance Teams
- Kohl's Cares, Starbucks, Target – are just a few of the business that give back with volunteers and donations
- National Honor Society or service club students from the local high school
- Volunteermatch.org (announce your volunteer needs here)

Time spent and lessons learned are important elements of every event. Keep track of the time given by your volunteers and be sure to have a post event "wrap-up" meeting to discuss what was great about your event and what elements may need improvement. You will find this information extremely helpful for future events, and the WSA learns from you too!. Please be sure to track the hours spent on the event by you and your committee and report that and the lessons learned to the WSA office upon completion of your event. This information will be collected in the event follow-up survey.

Sponsor Solicitation

All of the materials you'll need to reach out to sponsors and donors is included on the [Additional Resources](#) page on the WSA website. There you will find a request letter, full color brochure, and our 501(c)(3) designation letter should you need documentation for a sponsor. Start talking to people early - some companies take several weeks to process requests. Friends and family are always great resources for additional contacts (sponsors and auction donations), ideas and support.

Suggestions to get you started:

- It's all about connections. Who do you know? Can they put you in touch with the right person?
- Your child's therapists and physicians are often eager to make a donation.
- Many companies offer volunteer/match programs that can help increase your donations and support. Reach out to family and friends to see if their companies have programs they may be willing to contact on your behalf.
- Costco and Sam's Club often donate bottles of water. Applications should be submitted months in advance if possible to ensure success.
- Do you have a market or grocer you frequent? They are another great resource for food or beverages.
- Do you have a friend who owns a small business?
- Don't let hearing NO discourage you from asking others!

When approaching companies for sponsorships, some may wish to have recognition at the event. Below are some sponsorship options - they should be offered for different levels of sponsorship. These levels will be outlined in the sponsorship brochure.

- Company logo on a banner or print material
- Vendor table at event (ex: Sam's Club donates water and has a table selling memberships at event)
- Company logo on walk shirt
- Company print material in registration bags
- Company logo on online event registration page

PR & Marketing For Larger Events & Fundraisers

Press Releases

Events are a great way to obtain awareness - and not just for your event, but for Williams syndrome too. Send a request for a feature story on Williams syndrome several weeks in advance of your event. Be sure to include information on local families who will be willing to share their story along with you, if there are others in the area. Press releases specifically about the event should be sent 1-2 weeks prior to the event date and followed up by phone. The WSA has [press release templates](#) available on the Additional Resources webpage (both general and individual walk related) for your use. The WSA national office is also happy to help you prepare a customized press release and speak with writers to provide facts on WS and the WSA.

Media/Press Involvement

Depending on the size of your event, the local media can and should be contacted. Reaching out via social media can be an effective way to make that contact. If you are comfortable doing this on your own, feel free. Otherwise, please contact [Communications](#) at the WSA for support.

Social Media

Facebook is a valuable resource when trying to get the word out about your event. The national office will create an event page and post the event on the applicable [WSA Facebook pages](#). Encourage member families to comment, share, and post.



Emails

The WSA national office will highlight your event in an email blast to your entire area. This email will include all of your event details including the registration link and the event flyer.

If you have any special e-mail needs such as a parking map or venue information for a larger event such as a walk, please [use this form](#) to communicate this with the WSA Communications Associate, who will partner with you to create the email.

Vendor or Sponsor Recognition

If you will have vendors or sponsors at your event, such as local businesses etc., it is helpful to know so the vendors can be tagged and thanked in any social media posts. Please [use this form](#) to share your vendor and sponsor information with Communications.

Capturing Photographs of the Event

Please encourage photo taking at the event. Take a mix of individual families and group photos. When possible, designate an official photographer. The photographer doesn't have to be a pro or have a fancy camera, but they should be dedicated to taking LOTS of photos. When the event is complete, please upload your photos on the [WSA Google Drive](#).

All WSA-created event flyers will contain this disclaimer:

Photos taken at WSA events are often published on social media websites. If you do not wish to have your child's photo published on any of the WSAs social media please let us know prior to the event by writing to: info@williams-syndrome.org or calling 800-806-1871. The WSA does not oversee the publishing of photos, comments etc. by its members on their personal social media accounts. To all event attendees: if you plan to publish any of your photos personally via social media accounts or photo album sites like Snapfish, etc. please be sure to get the permission of all families involved prior to doing so. Thank you.

Logo Usage and Approval

A strong, well-defined corporate brand identity is one of an organization's most valuable and powerful assets. The WSA logo is a critical component in shaping our image and reputation as a leader in the area of Williams syndrome. It is important that we work together to ensure that the WSA brand stands out clearly and consistently in both internal and external communications.

Prior to using the WSA logo on any signage, communications, or items you may display or sell, you must obtain permission. To obtain permission, please [complete this form](#) which will collect your contact information and how you intend to use the requested logo. Upon approval, we will email you the logo in the format you indicated on the form. Until you receive approval, please refrain from using the requested logo.

Proof of Insurance

The Williams Syndrome Association's General Liability Insurance Coverage will extend via special rider to cover special events we host. This [certificate of liability](#) is only a summary of the coverage currently in place. Certificates do not guarantee, confirm or extend coverage and should be used for reference only.

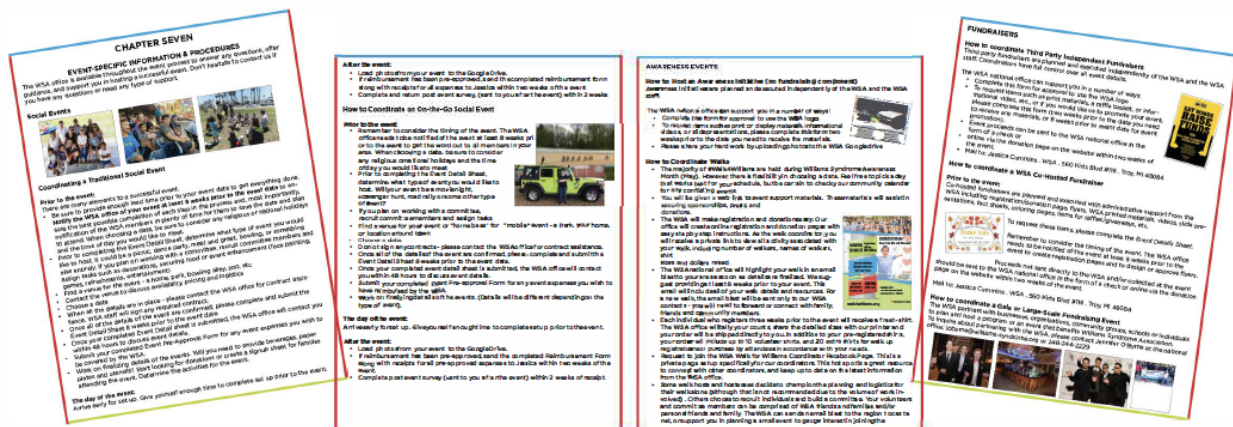
When scheduling an event, please ask for an outline of insurance coverage required to secure the location or venue. Please [contact the WSA national office](#) with this information so we can prepare the necessary documents to secure the venue. Keep in mind this process typically requires 48 hours for processing.

Event-Specific Procedure Guides

On the WSA website, you'll find guides for any event you may consider hosting:

- [Step-By-Step Guide to Social Events](#)
- [Step-By-Step Guide to Virtual Social Events](#)
- [Step By Step Guide to WSA Co-hosted Fundraisers](#)
- [Step By Step Guide to Third Party Independent Fundraisers](#)
- [Step-By-Step Guide to Walks](#)
- [How to Host a Movie Night](#)
- [How to Host Virtual BINGO](#)
- [How to Plan a Scavenger Hunt](#)
- [How To Plan a Road Rally](#)
- [Golf Tournament Quick Reference Planning Guide](#)

The WSA office is available throughout the process to answer any questions, offer guidance, and support you in hosting a successful event. Don't hesitate to [contact us](#) if you have any questions or need any type of support.



EXPENSE GUIDELINES

Each walk host/hostess is provided with an operating budget based on the size and the anticipated income for their event. Expenses are generally kept within 10% or less of expected gross proceeds. All expenses must be pre-approved. Typical expenses are, location rental fees, food and beverage or event enhancement activities. You must supply the WSA with receipts, invoices or contracts to justify the expenses and the WSA office will reimburse you. Or you can send the contracts and/or invoice directly to us for signature and payment.

Event Budget

Each event has a base budget, which is determined by the event type, a base amount per region, additional funding per family in the region, then an adjustment for cost of living in that area. That amount is then further refined based on the venue cost, "expected" attendance, and fundraising capacity of attendees (where applicable). The WSA office will provide event hosts with the budget following a review of submitted materials. Once approved, this budget will guide allowable expenses for each region. The goal is to ensure that the social events held in each region each year reach as many members in as much of the region as possible.

If you'd like to host an event in your area, reach out to the WSA [national office](#) for more information.

Expense Pre-Approval

When an event is pre-approved during the annual budget process, it does not need an additional approval to use budgeted funds. The funds for the event may be used for any type of expenditure, including food, beverages, paper goods, entertainment, educational speaker, venue rental, etc. The goal will always be to end the year with a balanced or positive budget. Careful planning, monitoring of expenses, and in-kind contributions are key.

Any event hosted that was not pre-approved during the budgeting process will be reimbursed only with pre-approval by the national office. Please follow the process in the [Event-Specific Procedures](#) section to submit for pre-approval.

Cash Handling

For most events and fundraisers, registration fees and/or donations will be collected primarily through online registration. Some events, particularly fundraisers, may collect cash for on-site registration, the purchase of WSA store items, donations, or raffle tickets. It is crucial that cash collected is accurately tracked and accounted for at your event. Here are some cash handling tips:

- Ensure you have extra cash on hand prior to the event. This will allow you to easily make change for anyone who may need it. Carefully document how much cash you start with, (have someone else count and verify the amount), and write it down so it can be accounted for at the end of the event.
- Be prepared with hand-written receipts for anyone who may need one.
- Assign a specific person/people to handle cash. If you plan to collect cash in multiple locations, or for multiple purposes, try to keep a separate cash box for each purpose. For example, keep separate cash boxes for each of these: WSA store items, donations, registration, bake sale, raffle tickets, 50/50 tickets, etc.
- If you expect to take in a large amount of cash during your event, have one volunteer dedicated to circulating around to each cash box and removing excess cash. That volunteer will document how much cash they remove, so it can be accounted for at the end of the event.
- Never leave your cash box unattended.
- At the end of the event, assign two trusted volunteers (preferably the primary event coordinator and one other person) to count and document the cash.
- After the cash has been counted and properly accounted for, it must be converted to a check or money order and submitted to the national office along with any other checks and any required paperwork for the event.

Cash Handling FAQs

Q. When the event is over, can I simply use the cash collected to settle expenses I've incurred for the event?

A. No. All money collected, should be returned to the national office within two weeks of the close of the event, along with a complete accounting of the income and expense for the event. It's important for the national office to be able to reconcile the income with any additional sales and/or raffle income collected on the day of the event. You will be able to note all your reimbursable expenses on your [Event Reimbursement Form](#) and the WSA will send you a check for that amount following the event. (Be sure to include all your expense receipts).

Q. We'd like to keep a portion of the money collected for local families. Is that OK?

A. No - it's not. In fact, It's illegal to hold out any of the money collected under the auspices of the WSA charitable license for personal distribution. Money collected for the WSA, can only be distributed by the WSA, generally through programs and support that are available to anyone. The WSA is also able to provide help to individuals through scholarships for special instructional programs (like musical lessons etc.) camps, conventions and post-secondary education, as well as grants for special programs and travel costs associated with special medical procedures for an individual with WS.

Q. Can people make their personal check out to me?

A. All checks must be made out to the Williams Syndrome Association. If not, the person writing the check will not get a tax-deduction and might not be as confident in the fact that their money is going to the association. We want everyone involved to know that their money is being used specifically for the programs and initiatives of the association.

Submitting Funds

Any funds donated in cash at an event or fundraiser should be submitted to the national office in the form of a check or money order, payable to the Williams Syndrome Association, along with any checks that have been written to the WSA, within 2 weeks of the event. Please indicate which event to credit in the memo line of the check or in associated paperwork.

Reimbursement of Expenses

Volunteer event hosts/hostesses are eligible for reimbursement of pre-approved, out-of-pocket expenses, incurred while engaging in volunteer service for the WSA. If expenses have been approved for reimbursement, volunteers must track and submit all receipts for those expenses. Reimbursement requests must be submitted to the WSA office within two weeks of the event.

- Reimbursement form must be completed in its entirety (within two weeks of the event).
- Invoices and/or receipts must accompany the [reimbursement form](#) (reimbursement will not be possible without receipts).
- [In-Kind donation forms](#) (if applicable) should all be submitted immediately following the event.

Ways to submit reimbursement:

- Mail to the WSA office: Attn Jessica Cummins, WSA 570 Kirts Blvd #223 Troy, MI 48084
- Email Jessica at jcummins@williams-syndrome.org. Include copies of all receipts.
- [Electronic Reimbursement Form](#)
- Fax: 248-244-2230

FREQUENTLY ASKED QUESTIONS

Q: Can I use the Williams Syndrome Association logo?

A: Yes, please do! However, please make sure you work with us when using the logo. It is important that we review all invitations and communications that include the WSA logo to ensure that branding guidelines are met. To obtain the logo and approval for its use, please [use this form](#) to submit your request to the national office. Remember that by using the logo you are letting your guests or contacts know that the WSA is a legitimate organization, and it's important to ensure that all information on the WSA is accurate. Be sure to send us the finished flyer etc. for final review before distributing.

Q: Can we sell event tickets on the WSA website?

A: Yes, this is an option. If you are selling tickets for your event, they can be sold through the website. You will need to provide all event information ahead of time and then direct invited guests to the WSA website. This will save you the trouble of collecting checks and having to forward them to the national office. Please contact the national office for more information.

Q: Do I need to register my event in my state or file for any forms?

A: If you host a raffle or auction, the WSA will help look into any legal issues that might need to be addressed. Obtaining licenses etc. can take 6-8 weeks – advanced planning is essential! The Williams Syndrome Association will help take care of anything like this. We are a tax-exempt non-profit organization, but often have to file for additional tax-exempt status based on the state.

Q: Can you help set-up conference calls for my committee?

A: We would be happy to help. Just call the national office for assistance. All we need to set things up for you is the reason for the call, date, time, and the number of participants.

Q: I want to host a virtual event, but I don't have a Zoom account. Can you help me?

A: We would be happy to help. Just call the national office for assistance.

Q: Will you help promote my event?

A: That's what we are here for! We are happy to include your event on the calendar, mention it in the website and send out a flyer and/or email to WSA families in the area.

Q: What about alerting the media?

A: The WSA office will provide press release samples if someone on your committee is comfortable modifying them or we will be happy to write them for you and help you identify the best media forum (print/radio/television) for your event.

Q: Who will design and distribute flyers?

A: The WSA office will design and distribute event flyers, with the exception those created by a restaurant or retailer for a third-party fundraiser.

Q: Can I open a bank account to manage funds collected at an event?

A: It is not proper for you to open a bank account with the WSA's name. Checks written to the association should be mailed to the WSA, and cash collected should be converted to a money order, cashier's check, or a personal check, which can be sent in along with the other checks collected.

Q: Can I sign checks over to the WSA?

A: Yes, checks can be signed over to the WSA. Endorse the back of the check if it's written out to you, then the check can be sent to the WSA.

Q: Who should a check be made payable to?

A: All checks should be made payable to WSA or Williams Syndrome Association. This ensures we are able to issue a tax donation letter.



WSA VOLUNTEER SUPPORT STAFF

The WSA staff is here to support you during your entire event-planning process. The list below provides a summary of which staff member you can contact directly for specific support. If you are unsure about who to contact, please do not hesitate to reach out to any of the staff members listed below and we will be happy to put you in touch with the correct office staff.

Michele Bauer - Volunteer & Event Associate

mbauer@williams-syndrome.org

Social events - initial event discussion and brain-storming, status of event, event pre-approval, registration updates, Facebook posts, walks, third party fundraisers (dine-to-donate), convention volunteers. Walks - initial contact, status of walk, walk coordinator packets, coordination of walks.

Jessica Cummins - Program Administrator

jcummins@williams-syndrome.org

Accounts payable; payment status, pre-approval and reimbursement forms, recipient of donations checks sent to the office, Liability insurance and additional required documents, graphic design of flyer, sponsorship logo upload to fundraising page

- Ways to submit reimbursement:
 - Mail to the the national office
 - Attn: Jessica Cummins , WSA 570 Kirts Blvd #223 Troy, MI 48084
 - Email Jessica Cummins jcummins@williams-syndrome.org
 - [Electronic Reimbursement Google form](#)
 - Fax: 248-244-2230

Laurie Fundukian - Communications Coordinator

lfundukian@williams-syndrome.org

Local event PR, special communications for larger events, sponsor and vendor details for social media shout outs, photographs after event

Sarah Giddings - Program Manager

sgiddings@williams-syndrome.org

Family Support Network, general program information, camp, convention.

Jennifer O'Byrne - Volunteer & Events Coordinator

jobyrne@williams-syndrome.org

Adventure Seeker events, convention, educational conferences, contracts, large fundraisers.

RESOURCES

There are tools & documents needed for all types of volunteer events. Most of these tools can also be found on the [Additional Event Coordinator Resources](#) page on the WSA website.

Additional Event Coordinator Resources

- [501\(c\)\(3\) IRS letter](#)
- [W-9 Form](#)
- [Certificate of Insurance certificate "Office Copy"](#)
- [Sample budget](#)
- [Solicitation letter for in-kind services](#)
- [WS/WSA messaging flyer](#)
- [Walk donation forms](#)
- [In-Kind donation form](#)
- [Credit Card Forms](#)
- [Expense Pre-approval form](#)
- [Reimbursement form](#)
- [Logo Usage Request form](#)
- [Email request form](#)
- [Vendor or Sponsor Recognition Request form](#)
- [Event Detail Sheet \(https://form.jotform.com/212865376718164\)](https://form.jotform.com/212865376718164)
- [Virtual Event Sheet \(https://form.jotform.com/213466309741154\)](https://form.jotform.com/213466309741154)

Printable Awareness Materials

- [WS Quick Info Card](#) (Business card size)
- [What is WS/WSA](#) (8.5 x 11, English) [What is WS/WSA](#) (8.5 x 11, Spanish)
- [WS Information Card](#)
- [Hands & Heart](#) awareness coloring sheet (8.5 x 11)
- [Shareable WS information cards](#)
- [Info Lawn Sign](#)

