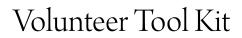
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Spring 2019



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School of Communication

Honors Research Project

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Committees, Location, Guest List, Mailings, Food and Beverage, Silent Au	uction, Budget,
Itinerary, Promotion, and Evaluation	

Overview

The Williams Syndrome Association is a nonprofit organization that helps raise funds and awareness about Williams syndrome. Williams syndrome is a disorder that is not very well known and has a lot of unique challenges associated with it. Individuals with Williams syndrome have serious health concerns and tend to be extremely friendly, outgoing, and empathetic. The Williams Syndrome Association is dedicated to raising funds to aid research, creating awareness for the disorder, and providing support to families that are affected by the disorder. The association recruits volunteers to put on an annual Walk for Williams Syndrome in their area. These events account for the majority of their fundraising and occur all across the country. This document is intended to assist the volunteer in the event planning process, and therefore take extra work off of the association.

The success of fundraising events that are planned for non-profit organizations, such as the Williams Syndrome Association, are imperative for the sustainability of the organization and their cause. For volunteers that are new to planning a fundraising event, having a step by step guide would help ensure the confidence of the planner as well as aid in the success of the overall event, in turn helping the organization to meet their objectives. To create this project, I researched theories in organizational communication and public relations to help understand what gaps in the organizational structure of the association needed to be filled, and what public relations theories needed to be addressed, since events serve as a public relations tactic. This research aided in the creation of this worksheet-like document, which the volunteers, also called walk coordinators, could use to guide their planning.

2

Review of Literature

Williams Syndrome

Williams syndrome is a disorder "caused by deletion of the Williams-Beuren syndrome chromosome region, spanning 1.5 million to 1.8 million base pairs and containing 26 to 28 genes" (Pober, 2010, p. 239). While Williams syndrome has serious health concerns (like cardiovascular abnormalities), this disorder is often characterized by personality, behavioral and emotional traits. First and foremost, individuals with Williams syndrome are very friendly, social, and empathic. It is also very common for these individuals to enjoy music or be gifted musically. "In a seeming paradox, sensitivity to certain noises, particularly thunderstorms or fireworks, develops in up to 90% of cases" (Pober, 2010, p. 245). There is also a prevalence of anxiety, specifically anticipatory anxiety. These characteristics are important to take into consideration while planning events for Williams syndrome individuals and their family members, which will be explained further in the review (Pober, 2010).

Communication in Organizations

Communication is an important aspect of many contexts in life. Communication can be described differently in different contexts, such as interpersonal communication, intrapersonal communication, group communication, mass communication, and organizational communication. Managing work relationships and honing the ability to work as a strong team requires communication skills in interpersonal interactions and group settings, which affect organizational communication as a whole. Organizational communication is the "the process by which messages are exchanged between individuals, groups, teams, or other subunits within some larger organization" (Walter & Graham, 2017, p. 106).

3

Publics

When advertising events, outreach is most successful when the correct public is sought after. Determining who makes up the public, or "groups of people with shared interests related to organizations," (Kelleher, 2018, p. 2) through the use of demographic and psychographic information helps draw a crowd of people who are supportive and enthusiastic about a specific cause. Demographic information consists of age, gender, ethnicity, socioeconomic status, and vocation. Psychographics focus on behavior, religion, political views, and hobbies. Being able to narrow the focus with this information gives the event planner their key public, who will be the most invested in what the organization has to offer. Using demographic information can help pull in families who are affected by Williams syndrome (Wilcox et al., 2013).

For the Williams Syndrome Association, a key public is families and friends who are affected by Williams syndrome and want to help support their cause. This public, the volunteers, typically will put on Walks for Williams Syndrome. Robert Ristino (2007), author of the *Communication with External Publics: Managing Public Opinion and Behavior*, quotes Cutlip, Center and Broom's objectives for nonprofits in public relations:

- 1. Earning public acceptance of an agency's mission, new ideas and new concepts.
- 2. Creating a favorable environment for fund raising activities.
- Encouraging volunteerism in a climate where there is growing competition for people's time and energy.
- 4. Promoting programs and services for those who need them most.
- Developing communication channels for the most disadvantaged groups in society (Ristino, 2007, p. 58).

VOLUNTEER TOOL KIT

When it comes to the walks that the Williams Syndrome Association puts on, numbers one through three are imperative for keeping the involvement of the volunteers that put on a walk. More often than not, they already have accepted the mission and values of the Williams Syndrome Association. Creating a favorable environment for them to work in (i.e. an environment that empowers them and gives them adequate support) as well as continually encouraging them to volunteer with the Williams Syndrome Association is necessary in keeping their involvement with the organization.

Theories. The situational theory of publics and the theory of reasoned action both can help explain the impact of the behavior of publics. The first theory, the situational theory of publics, "provides a framework for exploring the various factors involved in different publics' attitudes and behaviors toward an organization based on their perceptions of an issue or situation" (McKeever, 2013, p. 309). This theory focuses on the difference between active and passive publics, and how each public receives information. Active publics seek out information on a given topic and are therefore more likely to "engage in a behavior to do something about the situation" (McKeever, 2013, p. 309). This is the public the Williams Syndrome Association needs to focus on for their potential volunteers - the individuals that are actively searching for more information and ways to get involved.

The theory of reasoned action looks at the individuals' intention towards the behavior. They may feel obligated because they have been impacted by Williams syndrome, that should volunteer, or that other people are going to expect it of them (McKever, 2013). This feeling of obligation may push them into a volunteer role, but it is then the Williams Syndrome Association's responsibility to keep them engaged and change their intention in the future; encouraging them to stay involved.

5

Event Planning Process

Event planning is used as a tactic in many public relations campaigns. The prevalence of event planning, especially in the form of fundraising events, in healthcare organizations makes it a topic that is important to understand. From Judy Allen's book *Event Planning*, there is a lot of information that has already been compiled in regard to the event planning process. Allen goes in to detail explaining the process including: event vision, creating a critical path, timing, location, venue requirements, transportation, guest arrival, the guest list, food and beverage, and entertainment. She specifically breaks down each of these key concepts to help her audience understand the specific characteristics of each section (Allen, 2009).

Event Vision. The event vision includes five design principles: elements, essentials, environment, energy, and emotion. These principles are important to the overall development of the event and the audience perception. To better understand the five design principles and the breadth of what they cover, I have broken them each down:

- Elements *All of the parts that make up the event* The elements are the big picture ideas that the event planner visualizes their event having. The elements include: transportation of guests, accommodation of guests, shipping of items, set up of the venue, rehearsal space, cost of labor and staffing, and teardown of the event.
- Essentials *The "must-haves"* The essentials are the nonnegotiable pieces of the event. These include hard costs such as transportation, lodging, and venue costs, and items, decorations, and more that would help make the event meaningful and memorable.
- Environment *The venue and style* The environment can be broken down into the venue and the style. The venue can be hotels, convention centers, museums, country clubs, parks, and more. The style can be traditional, classic, modern, country, cultural,

formal elegance, casual elegance, romantic, fun, intimate, outdoor, themed, seasonal, holiday, beach, sports, etc.

- 4. Energy *The mood you will create* What the event planner chooses to do for the elements, essentials, and environment will help set the mood for the event. The energy at events are normally positive or negative, and making the right decisions about the room size, the layout, and the other elements, will help keep the energy positive.
- 5. Emotion *The feelings your guests should have* The emotion of the event should be a direct effect of the style and theme the event planner chooses for their event. Judy Allen gives the example of a romantic style evoking "feelings of tenderness, softness, intimacy, all wrapped up in love." While the style is romantic, the actual feelings the guests have are tenderness and intimacy.

It is also important to take into consideration the five senses, and how each sense will be used at an event. "Individuals attending a meeting or event use all five of their senses—hearing, sight, touch, smell, and taste—thereby becoming more emotionally involved in this process" (Wilcox, Cameron, Reber & Shin, 2013, p. 268). Because of the impact the senses have on attendees' emotional involvement, and the certain sensitivities individuals with Williams syndrome can have, it is important to tailor these sensory items to them. Certain loud noises should be avoided as much as possible. On the other hand, introducing music into the event should be considered this entertainment would be appropriate for the key publics demographics (Allen, 2009).

The Critical Path. The critical path is a master schedule of events that includes all deadlines for the event planner, their team, and all of the hired vendors. Having this detailed document helps keep everyone on schedule and in-the-know for the entire process, from day one through the evaluation of the event. The more detailed and realistic this document is, the more

accurate all parties can meet their deadlines. Allen (2009) lists twelve steps detailing how to compose the critical path, in order to be successful. Rather than listing out all twelve steps in the tool kit I created, I set up a template that the volunteer can use to walk them through the creation of the critical path.

Location. Site selection is critical for success of the event. It is important that the location is a continuation of the event vision. Even more than matching the theme/style of the event, the location must be conducive to the amenities that are needed. Such amenities could be private changing rooms, a stage, access to power, internet connection, or the ability to bring in a stage or sound system. Special location/venue considerations for Williams syndrome events may include a closed off or private location that does not have any other events or foot traffic. The sociability of individuals with Williams syndrome can lead to wandering and approaching strangers. Keeping the event in a more private location can help encourage these individuals to be themselves while relieving fears that family members may have in a public setting (Allen, 2009).

Fundraising. Fundraising is a topic that is often under discussed and under researched in the field of Public Relations. This "critical function for... nonprofit organizations" (Kelly, 1992, p. 20) is not only lacking in relevant research, it also is not well defined by researchers and academics as to its role in public relations. While this source is older, the author brings up an important point about the role of fundraising not being clearly defined. Kelly quotes the text *Effective Public Relations* saying, "fund-raising and membership... are a part of the larger organizational function--public relations" (p. 19-20). She also quotes their contradictory statement:

It is the public relations task to provide a favorable climate for the fund raiser, usually a specialist. The two functions must work in close cooperation, but as a general rule it is best not to combine the functions, whether in a university or in the Alliance for the Arts (p. 20).

Kelly continues to explain this contradiction and the prevalence - or lack thereof - of fundraising education in public relations curriculum. Her study concluded that 68 percent of schools that were surveyed believe that fundraising should be taught as a part of public relations, but that only 12 percent of institutions have a course dedicated just to fundraising (Kelly, 1992).

Methodology

For my project, I created a document that walks an event volunteer through the event planning process, and the specifics of each step. In this I included specific information on Walks for Williams, example sponsorship letters, additional event ideas, information on what Williams syndrome is, a sample budget with spending breakdowns, a press release, a donation form, a walk registration form, the Williams Syndrome Association tax form, and example thank-you letters. Throughout the guide I explain not just who the public is, but why it is important to know your public as well as the difference between demographic and psychographic information. Helping the volunteer understand what public to have, and how to get them involved in the event, will help the success of the fundraiser. I also use the above research to make this document into an effective tool that will help strengthen the quality of communication from the Williams Syndrome Association to the volunteer.

I hope that this project will help provide more insight into the importance of fundraising in the area of public relations. While research is currently lacking in the area of fundraising in a public relations setting, I intend to use this project to analyze the public relations function of fundraising and the organizational structure of the fundraising team. Each piece of my research had an impact of the final result of my project.

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Description and Rationale

For my honors project, I created educational materials for new volunteers that work with the Williams Syndrome Association (WSA). These educational materials will serve as a step by step guide that walks these new volunteers through the event planning process to create a successful fundraiser. This Volunteer Tool-Kit will be something that the Williams Syndrome Association could use for all of their volunteers, regardless of the type of fundraiser.

Currently, the Williams Syndrome Association generates all of its funds through fundraisers organized by volunteers across the country—the main fundraiser being Walks for Williams Syndrome. Currently, the various walks bring in a range of donations, with some raising \$2,500 and others raising \$80,000 or more. One cause of such a dramatic range of funds raised could be the number of years of experience the event coordinator has. However, having a tool that gives all of the walk coordinators a plethora of clear and up-to-date information could help boost their funds raised as well as boost their confidence as a coordinator. Helping volunteers feel more secure in the work they will be doing should help the Williams Syndrome Association retain their volunteers, which is vital to their overall fundraising success.

Since the main source of funds raised comes from walks, this tool-kit is truly targeted towards the walk coordinators. With few edits, the tool-kit can be transformed for other volunteers to use while planning events. However, this is designed for the walk coordinators, and includes many resources that would be provided to the coordinators, in one easy to follow document. I know that the Williams Syndrome Association is thankful for all of the volunteers that pour a lot of time into their events and is thankful for the funds they raise. They have chosen to take on a large role in supporting those affected by Williams syndrome; and most of the time it is for someone close to their heart. I am thankful to have been able to work on this project to support my family friend, Eden Cole. Eden is eleven years old and has Williams syndrome. Her light makes this world a better place, and I am so glad that I was able to create something that honors her spirit and her love for everyone around her. This project gave me a great opportunity to support Eden as well as put my four years of education to use in a way that can make a positive difference in her life, as well as many others.

Reflection

Through the creation of the "Volunteer Tool Kit" for the Williams Syndrome Association, I have learned how to apply what I have learned over the course of the past four years at The University of Akron. While my major is Strategic and Organizational Communication, I very much have an interest in event planning. This project has been the perfect combination of applying the event planning process to an existing event and strengthening the organizational communication between the Williams Syndrome Association and their volunteers. This allowed me to use my knowledge in event planning to fill a void in the organizational communication. When I first spoke to the association about this project, I was told that there was a need for this tool kit for multiple reasons. This comes from both the standpoint of the volunteers and the Williams Syndrome Association.

From the standpoint of the volunteers, these individuals that step into the role of a walk coordinator often feel like they are in over their heads and lack confidence in their event. The walk coordinators needed to have extra support from the Williams Syndrome Association to build their confidence. This tool kit was inspired by the desire to give the walk coordinators specific event planning information, since many of them have never planned an event on their own, and to in turn increase their confidence in their abilities. When we talk about awareness to action, most of the volunteers have already become aware of the situation, and advocate for the Williams Syndrome Association. This extra support should help move more people to take action and put on their own event or continue to put on events. The theory of reasoned action also comes into play here. In my literature review, I talked about how a family member of someone with Williams syndrome may be compelled to put a walk on in order to support their loved one. Sometimes, this can feel more like an obligation than a true desire to plan an event. Having this tool kit should help these individuals feel well equipped and help them enjoy the planning process, in turn, creating a volunteer who is excited to plan the event year after year.

I used what I learned from the Special Topics: Event Planning course as well as from Judy Allen's book *Event Planning*, to create the overall design of the tool kit. In the book, the concepts build on each other in the same progression of how one should plan their event. The progression of the tool kit is: Contact Sheet/Vendor List, Vision and Timing, Location, Guest List, Mailings, Food and Beverage, Budget, Itinerary, Promotion, and Evaluation. This mirrors Judy Allen's structure of her book. In the class Special Topics: Event Planning, I created an event plan, and I used that event plan to also guide the creation of the volunteer tool kit.

Cyndra Cole, a WSA Board Member, and her colleagues helped provide information about the Williams Syndrome Association to be included in the tool kit. The information in the introduction section of the tool kit helped provide insight into how to tailor the event planning information to the Walks for Williams. Some of the specific sections that were added to reflect the needs of this event were the Forming Committees section (page 21) and the Silent Auction section (page 30). Some of the other sections, like the Mailings (page 25) and Budget (page 31), were sections that are necessary for any event, however, I was able to make more specific because of the information provided by the association. The association also gave me insight into the need to better support their volunteers.

From the standpoint of the Williams Syndrome Association, having a Volunteer Tool Kit would be one way to better support their volunteers. This has two major benefits to the association. First, the increased confidence in the volunteers helps with their retention and ultimately helps them reach their fundraising goals. Second, this helps take some pressure off of the very small staff the association has. When I spoke to the association, I was able to analyze their network roles and see how exactly the communication was occurring between the association and the volunteers. This tool kit should strengthen the link and the communication between both parties. Giving their volunteers more independence allows the individual(s) that supervise fundraising grow their fundraising tactics, which also helps them meet their fundraising goals.

My intention for this tool kit is for the Williams Syndrome Association to distribute it to every volunteer that registers to put on a Walk for Williams Syndrome. The volunteer will then be able to learn about the event planning process, fill in and easily keep track of their progress, and have a clearer way to ask for help. Having each section broken down and in order of how the planning should progress should help the volunteer clearly communicate what they need help with when they come to a bump in the road. They can send a copy of the planning they have to the association for guidance, reference a page number, or just understand the language that is associated with event planning better. This way the communication between the Williams Syndrome Association and the volunteer is much clearer on both ends.

I am excited to see how this helps the Williams Syndrome Association grow their events. They work very hard to raise funds that will benefit the Williams syndrome community, and I am very pleased that I had the opportunity to create something that should help make their jobs a bit easier, so that they can keep impacting their community!

16

VOLUNTEER TOOL KIT

Appendix A

Project: Volunteer Tool Kit

Lydia Brooks

The University of Akron

VOLUNTEER TOOL KIT

The Williams Syndrome Association

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Dear Walk Coordinator,

First, congratulations on putting on your own Walk for Williams! You are making such a big impact on the Williams Syndrome Association and helping the Williams Syndrome Association fund many important research initiatives. This tool kit is intended to be just that: a tool that you can use to organize your thoughts, plans, successes, and areas for improvement. This guide should help walk you through the event planning process, give you valuable resources to use, and serve as a way to document your planning—so that next year, you have a plan to go off of!

In the introduction of this tool kit, I have included background information on Williams syndrome, the mission of the Williams Syndrome Association, and background information on planning fundraising events. All of this should help give you a comprehensive background to then put together your walk!

In the following section is the tool kit. This tool kit is comprised of ten sections that are listed out in the table of contents. As you progress through each section, you will be led through the planning of your event. My suggestion to you is to record everything you can within this document. This will help you with two things; first, you will have documentation of all of the planning you did so that if any issues arise, you can reference your work, and second, as you continue to put on more events, you have a record of who you worked with, what your timeline was, and what adjustments you would make.

I am excited for you in your journey of planning a Walk for Williams! Thank you so much for supporting the Williams Syndrome Association, and for taking on this amazing event!

Happy planning,

Lydia Brooks

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INTRODUCTION

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What Is Williams Syndrome?

Williams syndrome is a genetic condition that is present at birth and can affect anyone. It is characterized by medical and cognitive problems, including cardiovascular disease, developmental delays, and learning disabilities. These occur side by side with striking verbal abilities, highly social personalities and an affinity for music.

Williams syndrome affects 1 in 10,000 people worldwide – an estimated 20,000 to 30,000 people in the United States. It is known to occur equally in both males and females and in every culture.

Unlike disorders that can make connecting with your child difficult, children with Williams syndrome tend to be social, friendly and endearing. Parents often say they could not have imagined the joy and perspective their child with Williams syndrome has brought into their lives. Nearly everyone with Williams syndrome loves music, and for some, there is a musicality and eventual talent for music that is far greater than would be expected based on general functioning levels.

There are major struggles as well. Many babies have life-threatening cardiovascular problems. Children with WS need costly and ongoing medical care, and early interventions (such as speech or occupational therapy) that may not be covered by insurance or state funding. As they grow, they struggle with things like spatial relations, numbers and abstract reasoning, which can make daily tasks a challenge. And as adults, most people with WS need supportive housing to live to their fullest potential. Just as important are opportunities for social interaction. Adults with Williams syndrome often experience intense isolation which can lead to depression. They are extremely sociable and experience the normal need to connect with others; however, people with Williams syndrome often don't process nuanced social cues and this makes it difficult to form lasting relationships.

Other characteristics common to Williams syndrome are

- Hypercalcemia (elevated blood calcium levels)
- o Low birth-weight / slow weight gain
- o Feeding problems
- Dental abnormalities
- o Kidney abnormalities
- Hernias Hyperacusis (sensitive hearing)
- Musculoskeletal problems



Williams Syndrome Association Mission Statement and Values

The Williams Syndrome Association (WSA) advances 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 embrace the following core values:

- Names not Labels: Educate and advocate for the full and welcoming acceptance of individuals with Williams syndrome in educational, work, and community settings by maintaining an inclusive organizational environment that embraces diversity and the individual, as well as the collective needs of our members.
- Empowerment and Optimism: Equip members with the resources and support needed to make decisions and achieve their dreams while maintaining a positive outlook and belief in all that is possible.
- Collaboration, Respect and Vision: Foster a forward-thinking organizational mindset that promotes partnerships with public and private organizations, as well as medical, therapeutic, and educational experts, to maximize reach and impact.

Elevator Pitches

It is important when talking to potential donors and sponsors to be able to give a quick and comprehensive overview of what Williams syndrome is and who the Williams Syndrome Association is. These are often referred to as an elevator pitch, since it is typically a 30 second spiel that could be given in the length of an elevator ride.

Williams Syndrome

WS is a genetic disorder present at birth that can affect anyone. Medical and developmental problems, including cardiovascular disease and learning disabilities, typically occur side-by-side with striking abilities such as heightened music and social connections.

Williams Syndrome Association

The Williams Syndrome Association is the most comprehensive resource for people and families living with WS as well as doctors, researchers and educators. The WSA provides the resources and referrals that families need, and a strong and supportive community with which to connect throughout their child's life.



Williams Syndrome Awareness Month

WS Awareness is now in its 10th year – and this year we have 35+ walks/awareness events across the country. We are reaching approximately 10,000 people at the walks and other events, and tens of thousands more through media coverage—please spread the word! Awareness events account for nearly 2/3 of the total fundraising income for the WSA – they are CRITICAL to our ability to provide direct support to more families each year and increase the number and quality of our programs, as well as fund research.

Throughout the years since we began our awareness/fundraising efforts, we have been able to increase the amount of scholarship/financial assistance and research support from roughly \$50,000 per year to approximately \$400,000 currently, as well as sponsor free conferences for educators, and expand our assistive technology and housing initiatives.

86 cents of every dollar raised for the WSA goes directly to scholarships, grants and programs.

Breakdown of Spending

- o 35% Education
- o 20% Special Initiatives & Enrichment
- o 31% Research & Scholarships
- o 14% Fundraising & Administration



Ways to Volunteer – Additional Fundraising Event Ideas

Create an Online Campaign

If you aren't attending a walk in your area but still want to create an online donation page like the walk teams have, we can help! Your page can feature your son or daughter and include a story and photos. Please contact us and we'll set it up in our system! A campaign page is a great fit for volunteers who don't have the time or geographic locale to organize an event but are interested in raising money and generating awareness for Williams syndrome.

Dine to Donate / Shop to Donate

Many restaurants offer "dine to donate" fundraisers for charity. You choose a date and invite your friends/contacts to eat at the restaurant that night. The restaurant then donates 10-20% of the evening's proceeds to the WSA. 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! Some retail chains such as Alex and Ani, and many in-home retailers such as Pampered Chef hold similar events. All you have to do is invite your friends and the salesperson will tell the mall about the line of items. After a fun evening, you will all have some great new purchases and a portion of the proceeds will be donated back to WSA.

Bake Sale

A bake sale is a great fit for anyone, including kids! Whether you hold the sale in your driveway, work with your child's school or host a bake sale at your church/gym/community center, it's easy to plan. All you need is a few great bakers to contribute items to sell and a few volunteers to run the table. After the sale, you can send a check for the total to 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. Participants make a donation to the WSA for the privilege or wearing jeans to work or a funny hat all day in school. Work with your HR department or school staff and ask if they would like to help support the WSA and your son or daughter.

Sell Williams Syndrome Merchandise

The WSA has a full store of branded items, including our popular stickers, pop sockets, magnets and tattoos. This is a great (and easy) fundraiser, and more importantly, a great way to get people talking about Williams syndrome. You can place an order with the WSA (online or by phone) for the number of wristbands you plan to sell. You may then choose to sell them for more than the purchase price in order to raise money for the WSA Simply send the proceeds to the Williams Syndrome Association after you (or your child/adult with Williams syndrome) completes the sale! Visit: williams-syndrome.org/catalog for products.



Ways to Volunteer – Awareness Activities

Would you prefer to simply spread the word about Williams syndrome? The list of ways to get involved in Awareness Month is endless! All you have to do is host an event or awareness initiative and then let us know how it went and/or mail a donation to the National Office!

Contact City Council / Mayor / State Representatives

Work to get WS on your local government's mind. Ask a member of your state government (Representative, Senator, Governor or local Mayor) to issue a proclamation, declaring May as Williams Syndrome Awareness Month and recognizing the great work of local volunteers and the national Williams Syndrome Association. We'll provide you with an information packet to present to your government representatives in support of your request.

Awareness Displays

This idea is perfect for those with a knack for the creative! Displays can be set up in school 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 aware- ness month are preferable, but if that time frame is not available, any time leading up to May will be fine. Awareness is perfect for ANY time of year! Displays often contain the following: photos of local individuals with Williams syndrome who folks may recognize; local events, general information about Williams syndrome and the WSA, illustrations or something 3Dto demonstrate the WS deletion, WSA materials, etc. The national office has resources to help you put together a great display. Don't hesitate to ask!

Presentations

Many parents and individuals with Williams syndrome take time during awareness month 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. We also have templates you can use for your presentation slides, complete with our branding colors! Email us: info@williamssyndrome.org

Making and Selling Items with the WSA Logo

Members and friends of the WSA are welcome to make items using our logo, though our WSA logo is copyrighted and we just ask for prior approval of usage before using to ensure it meets the guidelines. Here are some ideas of crafty members who have made lovely items to share/sell. Because buyers have an expectation that a portion will benefit the WSA, we ask that the amount donated is at least 5% of sale proceeds. Thank you!



Fundraising Overview

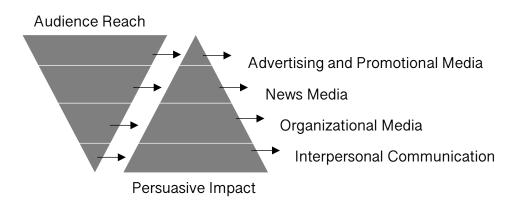
The WSA volunteers/families host walks across the country during the month of May, which raises funds for programming, research and scholarships. All events benefitting the WSA will be promoted via mail, email and internet (website and social media outlets).

Many regions have established walks and as they are finalized, will be listed here: https://williamssyndrome.org/williams-syndrome-awareness-events

Your walk will not only help with providing funds for programming, research, and scholarships, but it will also help bring awareness to Williams syndrome.

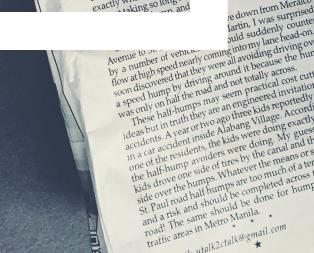
Audience Reach versus Persuasive Impact

Tactics that are used in a public relations plan (such as advertising, news media, organizational media, and events) have a variety of audiences they reach and persuasive impact on that audience. Generally, the more people the tactic will reach, the less persuasive it is to the audience, and vice versa. This idea can visually be represented by two pyramids:



Through the visual, you can see that interpersonal communication tactics have the smallest reach, but the most persuasive impact. Events fall in this category, which means your walk will give your audience the most persuasive impact! This gives you a great opportunity to teach them about Williams syndrome through activities, face to face conversations, and more! The goal of any walk is to raise awareness and funds for the association, and this gives you a great opportunity to do both!





TOOL KIT

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Contact Sheet/Vendor List

The first page in your tool kit is the contact sheet. This isn't going to be the first thing you fill out, it will take time to fill. But this is where you will keep track of all of your contacts: the Williams Syndrome Association, the venue coordinator, the food and beverage places, etc. Having everything placed in the beginning of your kit will give you a quick reference sheet for the planning and for quick reference on the day-of. Behind the contact sheet, add all of your contracts and written confirmations for quick reference.

Organization: Williams Syndrome Ossociation

Contact Name: Jennifer O'Byrne
Title/Position: Volunteer & Event Coordinator
Address: 570 Kirts Blvd Suite 223, Troy, Michigan 48084
Phone Number: 248-244-2229
Email Address: jobyrne@williams-syndrome.org
Emergency Number: 248-244-2229
Website: https://williams-syndrome.org/

Organization:

Contact Name:
itle/Position:
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Contact Name:	
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Phone Number:	
Email Address:	
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Vision and Timing

Goals and Objectives

A goal is "a global indication of how an issue should be resolved." There are three types of goals: reputation management, relationship management, and task management.

- Reputation management goals refer to strengthening, improving, or maintaining the perception of the organization
- Relationship management goals refer to the connection the organization has with its publics
- Task management goals refer to completing a certain thing or task

An objective is "a statement of specific outcomes expected for a public, indicating a way to more precisely conceptualize a goal." Objectives should be a continuation of the goal and should be SMART: Specific, Measurable, Achievable, Realistic, and Timed. For each goal, there are three objectives that should follow: awareness objectives, then acceptance objectives, and finally action objectives.

- Awareness objectives bring attention to the organizations publics
- Acceptance objectives mark an attitude change, where the public takes interest in what the organization is portraying
- Action objectives are when the public acts on the information they have been given

Putting it all together – here is an example of a goal and three objectives that help define that goal:

Goal One: Task Management Goal - Raise \$ 10,000 for the Williams Syndrome Ossociation

- Owareness: Bring increased awareness to the Okron area about Williams syndrome by sending out 1000 save the dates for the Walk for Williams six months prior to the event on May 1st.
- Occeptance: Have 300 confirmed RSVP's for the Walk for Williams eight weeks prior to the event on May 1st.
- Oction: Have 250 walkers show up on the day of the event (May 1st) to participate in the walk.



Writing your own goals

Goal One:
Is the goal a reputation management, relationship management, or task management?
Awareness Objective:
Acceptance Objective:
Action Objective:
Goal Two:
Is the goal a reputation management, relationship management, or task management?
Awareness Objective:
Acceptance Objective:
Action Objective:



Event Vision

The event vision is very important to the planning of the event. The vision is what should guide the decisions you make throughout the rest of the planning to help the event come together like the picture you have in your mind. The vision includes five design principles: the elements, the essentials, the environment, the energy, and the emotion. Take some time to plan out each principle.

Elements - All of the parts that make up the event

The elements are the big picture ideas that the event planner visualizes their event having. The elements include: transportation of guests, accommodation of guests, shipping of items, set up of the venue, rehearsal space, cost of labor and staffing, and teardown of the event.

My elements:

Essentials - The "must haves"

The essentials are the nonnegotiable pieces of the event. These include hard costs such as transportation, lodging, and venue costs, and items, decorations, and more that would help make the event meaningful and memorable.

My essentials:

Environment - The venue and style

The environment can be broken down into the venue and the style. The venue can be hotels, convention centers, museums, country clubs, parks, and more. The style can be traditional, classic, modern, country, cultural, formal elegance, casual elegance, romantic, fun, intimate, outdoor, themed, seasonal, holiday, beach, sports, etc.

My environment: _____



Energy – The mood you will create

What the event planner chooses to do for the elements, essentials, and environment will help set the mood for the event. The energy at events are normally positive or negative, and making the right decisions about the room size, the layout, and the other elements, will help keep the energy positive.

My energy: _____

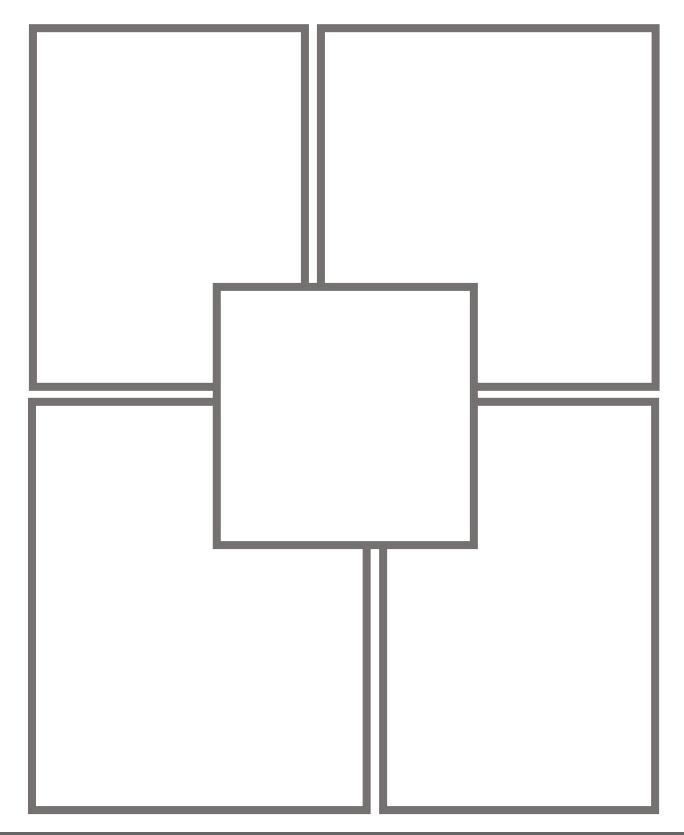
Emotion – The feelings your guests should have

The emotion of the event should be a direct effect of the style and theme the event planner chooses for their event. Judy Allen gives the example of a romantic style evoking "feelings of tenderness, softness, intimacy, all wrapped up in love." While the style is romantic, the actual feelings the guests have are tenderness and intimacy.

My emotion:



Insert photos that represent your vision for the event:





Theme

The entire event vision should support the theme of your event. Having a clear theme helps your vision become cohesive and helps show the audience how they should feel.

My theme:

Key Messaging

The key messaging is your "slogan." This should be a continuation of both the theme and the vision as a whole.

My key messaging:_____

Estimate Budget

Fill in below your expected budget, and the expenses you foresee.

Approximate Budget to Work With:

· · · · · · · · · · · · · · · · · · ·		
Item:	Cost:	

Yay! At this point, you have a picture of the event in your mind, and on paper!



Timing

When choosing the date and time of your event keep in mind holidays, local events happening around the time, and your audience. If you are inviting guests from out of town, be respectful of their travel time. And if you're inviting families, choose times that are kid-friendly.

Event Date and Time:

To create your event timeline, work backwards from your event date and fill in what you would like to have accomplished. Add in the deadline dates based off of your event date to create a calendar-like checklist. A few general things have already been filled in but add to this list to help keep you on track!

Pro tip: start at the bottom—the day of the event and work backwards to fill in all of the information!

12 months before: complete by

0

9-11 months before: complete by 6-8 months before: complete by Send out Save the Dates O

4-5 months before: complete by

- 0 0
- 0
- 0

19



2-3 months before: complete by

- o Send out invitations

2 months before: complete by

RSVP Date
o
o

1 month before: complete by

- 1-2 weeks before: complete by
 - Meeting with vendors check in to make sure everything is set
- A day before: complete by

The day of the event: complete by



Forming Committees

Forming committees is a great way to divide up the work to make the event planning more manageable. Each committee is should have a lead person—if you have a small number of people working on your event there may be only one person per committee, but if you have multiple people on each committee then each should have a lead "point person." Here are some committees you may want to include in your planning:

- Vendors (non-food)
- o Food and Beverage
- o Press and Raffle
- o Spreadsheets (registration)
- o Silent Auction
- o Publicity

You do not need to have each of these, and you can always add more to this! Depending on what areas you decide to make committees for, be sure to pass on the appropriate planning materials from this tool kit. Keep track of who has been placed on each committee here:

Committee:		
Members:		
Committee:		
Manahana		
Committee:		
Members:		
Committee:		
Members [.]		
Committee:		
Members:		



Location

When choosing the location for your event, it is important to make sure the venue meets the criteria of your "essentials." Be creative—and keep your audience in mind when making the decision.

Venue

Organization:
Contact Name:
itle/Position:
Address:
hone Number:
mail Address:
mergency Number:
Vebsite:

Pricing

What is the total pricing for the venue?	
Item:	Cost:

Onsite Amenities

What kind of amenities are provided by the venue?

Accessibility

Is the venue accessible to your audience?



Parking

Is parking free? Is it onsite or within walking distance? Can it hold the number of guests you will have?

How does the venue emphasize the vision?

Since the goal of your planning is to create an event that embodies your vision for the event, jot down here how your location choice strengthens the vision you have for your walk.

Put your contract for the venue in this workbook behind this page.

Walk Route

Once you have your walk route (or routes) planned out, paste your map here:



Guest List

Key Public

Your key public is the audience you want to attract to your event. Targeting your key public is much easier once you've determined who they are. Most likely, for this event, your key public will consist of local families that have been affected by Williams syndrome. You can write down your key public below:

To expand on this, we are going to write a guest profile. This is made up of your audience's demographics and psychographics. Demographics consist of age, vocation, ethnicity, gender, socioeconomic status, education level, marital status, family size, geographic location, and handicaps. Psychographics consist of behaviors, hobbies and interests, political views, religion, and sexual orientation.

Take a minute to list out the characteristics of your key public:

Media

Inviting the media to your event can be good publicity for your event and the Williams Syndrome Association. This is not something you have to do, but if you do decide to do so, you will have to consider how they will fit into the event. Do you want them to be a part of the walk, like your other guests? Will they be doing photography, videography, or conducting interviews? Make sure that you know what you want their role to be if they're going to be a part of the event!

Guest Count

What is your anticipated guest count?



Mailings

Invitation

When creating your invitations, be sure to include the name of your event, the event description, the date, time, and location, and the method of RSVP and the deadline to do so. You want your invitation to be easy to read and reflect the theme of your event. The invitation is the first impression your guests will have of your event, so make sure to use it to set the tone you want. If you are looking to design your own invitations, two online sites you can use are evite.com and canva.com. Insert your final invite below for your records!



The WSA logo may be used for awareness shirts, event posters, invites etc. as long as preapproval is received from the national office. The logo cannot be used for any type of private fundraising activity (not directly hosted by, or in partnership with, the WSA).

To obtain pre-approval simply send a draft of the design of your awareness item to info@williams-syndrome.org. Remember that the logo must "stand alone" – you cannot place any messaging or image on top of any part of the logo. Similarly, it should not be placed in the midst of a busy background.



Sponsorship Letter

On the following page is an example sponsorship letter. Sponsors can help support your event monetarily, or through donations of food, drinks, silent auction items, and more! Sending letters out is an effective way to reach a large number of people, but make sure to follow up! If a potential sponsor asks for the Williams Syndrome Association's 501(c)(3) information, the page following the solicitation letter contains that information.

You can draft potential sponsors here:





Name Address Address

Dear X,

I am writing to ask for your support of Williams Syndrome Awareness Month, taking place May 1 - 31, 2019.

Williams syndrome is a rare genetic condition that is present at birth and can affect anyone. It is characterized by medical problems, including cardiovascular disease, developmental delays, and learning disabilities. These occur side by side with striking verbal abilities, highly social personalities and an affinity for music.

The Williams Syndrome Association is the most comprehensive resource for people and families living with WS as well as doctors, researchers and educators. The WSA provides the resources and referrals that families need, and a strong and supportive community with which to connect throughout their child's life.

Williams Syndrome Awareness Month is nationally recognized with more than 100 events each year. Locally, we will be hosting ______ on ______. Will you consider ______? (List the type of support you would like here, such as "providing bagels and coffee for our walkers" or "sponsoring our walk picnic with a cash donation of XXX")

By joining forces with the WSA and local volunteers, you will be enhancing the future for all individuals with Williams syndrome. You will also be reinforcing your image as a philanthropic partner within the local community. All event sponsors are recognized in a variety of ways (Brochure attached).

I will follow-up with you shortly to answer any questions you may have. In the meantime, please feel free to visit the WSA website at *williams-syndrome.org*. Thank you for your time and consideration.

Sincerely,

Name WS Awareness Month Walk Coordinator Email Address

DEPARTMENT OF THE TREASURY

INTERNAL REVENUE SERVICE DISTRICT DIRECTOR P. O. BOX 2508 CINCINNATI, OH 45201

Date:

JUL 1 3 1998

Williams Syndrome Association Wood Crest Office Plaza 570 Kirts Blvd. Suite 223 Troy, MI 48084 Employer Identification Number: 22-3305007 DLN: 17053164788018 Contact Person: D. A. DOWNING Contact Telephone Number: (513) 241-5199 Our Letter Dated: January 1995 Addendum Applies: No

Dear Applicant:

This modifies our letter of the above date in which we stated that you would be treated as an organization that is not a private foundation until the expiration of your advance ruling period.

Your exempt status under section 501(a) of the Internal Revenue Code as an organization described in section 501(c)(3) is still in effect. Based on the information you submitted, we have determined that you are not a private foundation within the meaning of section 509(a) of the Code because you are an organization of the type described in section 509(a)(1) and 170(b)(1)(A)(vi).

Grantors and contributors may rely on this determination unless the Internal Revenue Service publishes notice to the contrary. However, if you lose your section 509(a)(1) status, a grantor or contributor may not rely on this determination if he or she was in part responsible for, or was aware of, the act or failure to act, or the substantial or material change on the part of the organization that resulted in your loss of such status, or if he or she acquired knowledge that the Internal Revenue Service had given notice that you would no longer be classified as a section 509(a)(1) organization.

If we have indicated in the heading of this letter that an addendum applies, the addendum enclosed is an integral part of this letter.

Because this letter could help resolve any questions about your private foundation status, please keep it in your permanent records.

If you have any questions, please contact the person whose name and telephone number are shown above.

Sincerely yours,

C. ashley Bulla

District Director

Food and Beverage

Type of Food

Here you will brainstorm what kind of food you want for your walk! While doing so, keep in mind the time of day you are hosting the event, if you will have seating, or if people will be standing while they eat, and what is appropriate for your audience. If your walk is in the morning, you should plan on breakfast items; and if you will not have seating, make sure it's something that can easily be eaten while standing!

Menu

Write your menu here, or attach an additional sheet:

Pricing

The hope is through sponsorships, you can get some of these items donated. Sometimes you will have to pay for some or all of those items, and you can include those prices here:

Food/Beverage	Your Estimates	Octual Cost
	\$	\$
	\$	\$
	\$	\$
	\$	\$



Silent Auction

Raffles and silent auctions are one of the most popular and cost-effective ways to raise money for a nonprofit organization. However, to make a raffle or auction successful, you must first secure desirable items.

The best place to start is to survey the members of your committee, family and friends and your WSA region. Every supporter could possibly have something of value to contribute to the prize pool. And if not, they may know somebody who does.

These are just a few examples:

- A handmade quilt or afghan
- Do you have a friend who sells Tupperware? Would they donate a cake carrier? You are certain to know someone willing to bake the cake
- A friend's cottage would make a great weekend get away
- A college student willing to donate Babysitting (for an event where everyone knows each other)
- o A chef willing to offer private in-home cooking lessons for 2 couples
- A basket of spirits each committee member donates one bottle of "spirits" to build an exciting party basket
- If you receive a handful of smaller items, try pairing them together to make one larger item
- A friend who owns a dealership may be willing to donate a convertible for a weekend or a lease for a year
- Does your company offer season tickets? Does a friend own some?

When reaching out to local businesses, begin canvassing your community now. Come prepared with a request letter, a copy of our 501c3, an information flyer and a donation form (for those wanting a tax receipt). Every business is a viable option and it never hurts to ask. Again, don't let NO discourage you, because another door will open.

Some popular items:

- Gift Certificates from restaurants, coffee shops or ice cream parlors, nail and hair salons
- Tickets to a show, a theatre or local players club
- o Doggie day care or boarding facility
- o Day pass to parks, zoos or beaches
- o Golfing, autographed memorabilia, or Cigar Packages



Budget

When creating your budget, be sure to include all of your event incomes and expenses. Your income should include all of your sponsorships, registration fees, and any additional sales (t-shirts and silent auction items). Expenses should include the venue, any rental items, décor, permits, invites, staffing, entertainment, staging, food and beverage, and promo. The hope is that some of the expenses will be donated by sponsors, or that sponsorship money will cover the expense. The lower the expenses, the higher percentage of income from the walk will be donated back to the Williams Syndrome Association. Fill in below the line item, your estimated expense or income, and then the actual cost once you have that number.

Event Proceeds	Your Estimates	Octual Cost
Tickets	\$	\$
T-shirt sales	\$	\$
	\$	\$
	\$	\$
	\$	\$
Sponsorships	Your Estimates	Octual Cost
Major sponsors	\$	\$
Minor sponsors	\$	\$
Other	\$	\$
	\$	\$
	\$	\$
Odditional Sales	Your Estimates	Octual Cost
Silent Ouction	\$	\$
	\$	\$
	\$	\$
	\$	\$
	\$	\$
Page Total:	\$	\$

Event Income



Event Expenses

Each walk is given an operating budget based on the size and the anticipated income. 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. Alternatively, you can send the contracts and/or invoice directly to us for signature and payment.

You are not authorized to sign any contract on behalf of the WSA. If you walk venue requires a contract and deposit etc, you should meet with the venue to discuss dates and all associated expenses, and then provide the contract to the WSA office. WSA staff will then complete the contract and handle any details and payments, listing you as the local contact person. **Do not reconcile your own receipts from monies collected. The WSA office must keep a formal count of all expenses and provide reimbursements.** Use your reconciliation envelope to organize all of the papers and documents. Following the walk, complete the attached form and return this envelope along with all donations, receipts and the WSA Banner to the WSA national office. Please DO NOT send cash. Convert all cash to a money order at your local bank or grocery store.

Site	Your Estimates	Octual Cost
	\$	\$
	\$	\$
	\$	\$
	\$	\$
Decorations	Your Estimates	Octual Cost
	\$	\$
	\$	\$
	\$	\$
	\$	\$
Food/Beverage	Your Estimates	Octual Cost
	\$	\$
	\$	\$
	\$	\$
	\$	\$



Prizes/Giveaways	Your Estimates	Octual Cost
	\$	\$
	\$	\$
	\$	\$
	\$	\$
Promotion	Your Estimates	Octual Cost
	\$	\$
	\$	\$
	\$	\$
	\$	\$
Page Total:	\$	\$

Event Expenses Cont.

Program	Your Estimates	Octual Cost
	\$	\$
	\$	\$
	\$	\$
	\$	\$
Other Expenses	Your Estimates	Octual Cost
	\$	\$
	\$	\$
	\$	\$
	\$	\$
	\$	\$
Page Total:	\$	\$
Total for all pages:	\$	\$

To keep a more detailed budget, consider using an excel document, where you can add and delete line items and format it to do your calculations for you. The WSA has a template you can use here: https://williams-syndrome.org/additional-awareness-month-resources



Itinerary

Your itinerary will help you keep track of everything happening before, during, and after your event. When you create your itinerary, you should include when you are doing your promotion, set-up (the "pre-event"), the event itself, and tear down (the "post-event"). Fill in the timeline for each to keep track of everything.

Pre-Event

The pre-event should include set up times specific to each role. For example, this should include when you will arrive, when each of your vendors will arrive, and the time it will take everyone to set up. Make sure set up happens in an order that works for everyone—like the tables should be set up before food is delivered.

Start Time	End Time	Task	Duration



During Event

During the event should be an hour by hour or event minute by minute breakdown of what is happening at the event. For your walk, this might include registration, the walk time, opening and closing of the silent auction, and time a performer takes the stage. Everything that is going on should have a time that gets tracked.

Start Time	End Time	Task	Duration

Print outs for during the event

The following attachments are for your use at the event. Make sure to have them printed and ready to go for the day of!



		ne Association, tion SA, Inc alk or mailed to the roy, MI 48084	All proceeds benefit the Williams Syndrome Association, a 501(c)3 Non-Profit Organization All checks should be payable to WSA, Inc Donations collected can be turned in at the walk or mailed to the WSA at 570 Kirts Boulevard, Suite 223, Troy, MI 48084	All proceeds All cl Donations collec WSA at 570	
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ASSOCIATION					Email:
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				ess:	Address:
				Walker's Name:	Walk

Walk up Registration Forms

NAME:				
ADDRESS:				
CITY:			ZIP:	
EMAIL:				
INDIVIDUAL REGISTRATION \$				
SELECT PAYMENT TYPE:	CASH	CREDIT CARD	/	CHECK/CHECK NUMBER
NAME :				
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Williams Syndrome Association Credit Card Payment Form



Billing Information (na	ame and add	lress as it appears on your cre	dit card statemer	nt):		
*Name:						
*Street Address:						
*City:			*State:	*Z	*Zip:	
Phone:		Email (credit card receipt wil	Email (credit card receipt will be emailed):			
Credit Cards Accepted:		*Credit Card Number:	*Credit Card Number:		*Expiration:	
					*CV2 #:	
*Payment for:		*Signature:				
Donation	\$					
Registration	\$					
WSA Store Item \$						
Auction	\$		All fields wit	h * are req	uired	
Total to be Charged	\$	Thank Yo	ou for your	suppo	rt of the WSA!	

Williams Syndrome Association Credit Card Payment Form



Billing Information (na	me and add	ress as it appears on your crea	lit card statemer	nt):		
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*Street Address:						
*City:			*State:	*Zip:		
Phone:		Email (credit card receipt will	Email (credit card receipt will be emailed):			
Credit Cards Accepted:		*Credit Card Number:	*Credit Card Number:		*Expiration:	
					*CV2 #:	
*Payment for:		*Signature:				
Donation \$						
Registration \$						
WSA Store Item \$						
Auction	\$		All fields wit	h * are require	d	
Total to be Charged	\$	Thank Yo	Thank You for your support of the WSA!			

Post Event

The post event should include tear down times specific to each role. This should for the most part be a reverse of the set up—any leftover food or catering equipment should be taken down before tables are removed.

Start Time	End Time	Task	Duration



Promotion

As soon as you have the date, time, and location for your event, you can start working on the promotion! Promotion is normally thought of as the invites that go out before the event, but you should do promotion through the event and after the conclusion of the event as well. Work through each event stage to create a timeline of the kind of promotion you will do.

Pre-Event

The pre-event promotion should include sending invites, distributing promotional materials, contacting the media, social media postings, and follow ups!

Date	Kind of Promotion

During Event

During the event promotion should include social media postings, hashtags, photos, videos, interviews, live media publicity, radio and/or TV! These should also be put into your itinerary for during the event.

Date	Kind of Promotion



During Event Continued

Date	Kind of Promotion

Post Event

The post event promotion should include follow up with attendees and sponsors, social media postings, contacting the media, and creating/updating promotional materials with the photos, videos, and interviews from the event, and press releases. Sample press releases can be found on the next two pages.

Date	Kind of Promotion



FROM: Williams Syndrome Association Contact: Terry Monkaba: (248)-244-2229 tmonkaba@williams-syndrome.org



For Immediate Release

WILLIAMS SYNDROME TO BE THE FOCUS OF EVENTS NATIONWIDE DURING THE MONTH OF MAY

More than 10,000 people in cities across the country expected to "Walk for Williams" in May

(Troy, MI) – Thousands are expected to join the Williams Syndrome Association (WSA) during the month of May to raise awareness for Williams syndrome (WS), a genetic condition that remains largely unknown to the general public, educators and many doctors. Included in the awareness events are walks in major cities across the U.S. including Boston, New York, Philadelphia, St. Louis, Detroit, and Houston.

Events are being held to increase community awareness and provide financial support for the Williams Syndrome Association, the nation's largest support organization for those with WS. Funds will be used to help finance critical research and scholarship programs for individuals with Williams syndrome. New research can lead to further insights about the disorder and new treatments for the future. Scientists are particularly interested in studying issues such as diabetes, hypertension and anxiety in Williams syndrome which may contribute to greater understanding of these problems in millions of other affected Americans.

Featured on 20/20 and MSNBC, Williams syndrome is characterized by medical and developmental delays, cardiovascular disease and learning disabilities. At the same time, people with Williams syndrome often have unique abilities, including advanced verbal skills, highly sociable personalities and an affinity for music. Children with Williams syndrome need costly, ongoing medical care and early interventions that may not be covered by insurance or state funding. In addition to research, the WSA's *Walks for Williams* during the month of May will provide funding for the Williams Syndrome Association's medical emergency fund, which provides financial support to families for expenses associated with costly medical treatments for their children.

About the Williams Syndrome Association

The Williams Syndrome Association (WSA) is a 501(c)(3) charitable organization formed in 1982 by family members of people living with the disorder. Today, the WSA is the most comprehensive resource for people and families living with Williams syndrome as well as doctors, researchers and educators. The association provides programs and support in the areas of education, enrichment and research. For more information on the Williams Syndrome Association, please visit www.williams-syndrome.org.

Williams Syndrome Association Contact: Terry Monkaba Executive Director www.williams-syndrome.org tmonkaba@williams-syndrome.org 1-800-806-1871 (toll-free)



MEDIA ADVISORY

Locally: [your info]

Walk For Williams: Oakland County Residents Help Raise Awareness of Williams Syndrome!

[Your community], May ... 2017: Individuals with Williams syndrome (WS) have extraordinary gifts and unique challenges. But not enough people know that. During a full month of activities in May, volunteers for the Williams Syndrome Association are working to inform our community and others across the country about Williams syndrome.

As part of the WS Awareness Month, *Walks for Williams* and other special events will take place in locations throughout the country. More than 10,000 people are expected to participate nationwide. Locally, a walk will be held at ..., from [Walk organizer] is organizing the local walk. [He or She] will be joined by [local committee members/school organizations etc.] to help "spread the word" about Williams syndrome and raise critical funding for research and scholarship programs. In addition to the Walk, activities at the event will include...

Featured on 20/20, MSNBC, and an episode of the television show *Chicago Med*, Williams syndrome is a genetic condition that is present at birth and can affect anyone. It is characterized by medical problems, including cardiovascular disease, developmental delays, and learning disabilities. These occur side by side with striking verbal abilities, highly social personalities and an affinity for music. Williams syndrome affects 1 in 10,000 people worldwide – an estimated 20,000 to 30,000 people in the United States. Unfortunately, many of these individuals are undiagnosed or misdiagnosed. Proper diagnosis is critical to acquiring the medical, therapeutic and educational treatments and strategies that dramatically improve the life of an individual with Williams syndrome.

Children with Williams need costly and ongoing medical care, and early interventions from speech, occupational and physical therapists that may not be covered by insurance or state funding. As they grow, children struggle with things like spatial relations, numbers and abstract reasoning, which can make daily tasks a challenge.

The Williams Syndrome Association is the most comprehensive resource for people and families living with Williams syndrome as well as doctors, researchers and educators. The WSA provides resources, support and the latest medical information to help children with WS today and throughout their lives. Awareness month activities will help fund the Williams Syndrome Association's research, medical emergency and scholarship funds. The medical fund provides financial support directly to families for expenses associated with costly medical procedures for their children. Scholarships are provided for summer enrichment, post-secondary and transition programs as well as grants to educational conferences and conventions.

Local residents are encouraged to come out and support families affected by Williams syndrome and the WSA. If you would like more information about this event [or to obtain a pledge form], please contact: [your contact information]. For more information about Williams syndrome go to **Williams-syndrome.org**.

Evaluation

The evaluation is the last, but a very important part of your event. This is where you assess the success of your event in comparison to the goals and objectives you set for your event. Write for each of your goals whether or not each objective was successful, and how they measured up (i.e. how each of the "SMART" details were met, exceeded, or not reached).

Example:

Goal One: Task Management Goal - Raise \$ 10,000 for the Williams Syndrome Ossociation

- Owareness: Bring increased awareness to the Okron area about Williams syndrome by sending out 1000 save the dates for the Walk for Williams six months prior to the event on May 1st.
- Occeptance: Have 300 confirmed RSVP's for the Walk for Williams eight weeks prior to the event on May 1st.
- Oction: Have 250 walkers show up on the day of the event (May 1st) to participate in the walk.

Awareness Objective – was it met? Yes st to bring increased awareness to the Okron area about Williams syndrome

Acceptance Objective - was it met? Yes How: Had 315 confirmed RSVP's for the Walk for Williams eight weeks prior, on March ^{1st}, for the event on May 1st

Action Objective – was it met? Yes How: Had 263 wakers attend the event on May 1st to participate in the wak

<u>Goal One</u>

Awareness Objective – was it met? How:

Acceptance Objective – was it met? How:

Action Objective – was it met?How:
<u>Goal Two</u>
Awareness Objective – was it met? How:
Acceptance Objective – was it met? How:
Action Objective wee it met?
Action Objective – was it met?How:

Use your evaluation to set new goals and objectives for next year!

