



Chasing Butterflies

THE WALK FOR TURNER SYNDROME

TSSUS National Fundraiser

12620 FM-1960 W, SteA4 #210~ Houston, TX 77065

Phone: 800-365-9944

www.turnersyndrome.org ~ email info@turnersyndrome.org





Dear TS Walk Coordinator:

Thank you for your interest in holding a walk that will support the Turner Syndrome Society of the United States (TSSUS) programs. All the programs we offer strive to advance our mission: to create awareness, promote research and support all persons touched by TS. We are so thrilled that you want to partner with us so we can make forward progress to “crush ignorance of TS.” We are amazed by the success of the walks in raising needed funds, but mostly because of how they assist in creating a supportive local community for those touched by TS.

The Chasing Butterflies: The Walk for TS is the signature national fundraiser for TSSUS and these guidelines will guide you in planning a successful Walk. Whether you are interested in holding a small walk with friends and family or aim to hold a public walk, we encourage you to add your own enthusiasm and creativity to make your walk memorable and exciting.

Please know that we are eager to work with you to make the experience as rewarding and successful as possible. In addition to these guidelines, we have many resources that may be helpful to you such as sample letters for donations/sponsors and personalized flyers. If you have ideas that are not addressed in these guidelines, please talk to us about them so we can offer any help or suggestions.

Enjoy the experience, have fun, and let us know how we can help!

Sincerely,

*Deborah Rios and
The Turner Syndrome Society of the US staff and board of directors
800-365-9944
deborah@turnersyndrome.org*

Chasing Butterflies: The Walk for TS Guidelines

Getting Started

1. Read this handbook to become familiar with the planning needs.
2. Gather a committee or team of volunteers to help you coordinate the walk; two walk helpers are required to assist you in your walk planning and to commit to volunteering the day of the walk.
3. Once TSSUS has received the walk notification form, you and your walk helpers will receive a call or email to discuss the planning process.

Initial Planning for the Walk Notification Form

1. Choose a date and time

- Choose a date and time that will offer the best opportunity for people to participate. A Saturday or Sunday may allow more individuals and families to participate. Take into consideration where your attendees will be coming from. If some people are driving 3 hours to walk, you probably don't want to begin at 8:00 am.
- Consider the weather during the time of year you will be holding your walk. If it is summer in the south, you probably don't want to hold a walk at noon or early afternoon.

2. Choose a location

- Be flexible. Have at least two options in case your desired location is not available or is too expensive to be considered (as determined by TSSUS.)
- Consider locations easily accessible so people won't have trouble finding your walk site. The place you choose may be best if it's near an interstate, highway, or town center, but keep in mind the safety of the walkers near busy streets or crossings.
- Determine the distance you want to walk. If your walk will have people of all ages participating, consider limiting the walk to 1 or 2 miles.
- Look for locations that are free or have minimal fees. If a location requires a fee or permit, TSSUS must pre-approve the fee before a commitment is made for the location. Allow additional time for permit requirements.
- TSSUS will provide a certificate of insurance directly to the venue if required.
- Suggestions of locations include parks, local schools, colleges, churches, zoos, and museums with outdoor space.

Paying For Your Walk

- The Chasing Butterflies Walk creates awareness and is a fundraiser. **All fees and expenses associated with the walk must be pre-approved by TSSUS.**
- Each walk may receive up to \$200.00 for venue-related expenses (deposits, fees, portable toilets, etc.) Additional expenses *may be* available depending on the purpose and pre-registration numbers on a case-by-case basis. All expenses, including venue-related ones, cannot exceed 25% of registration fee revenue.
- Additional expenses can include activities like face-painting, or products like drinking water. Asking local businesses for In-Kind Donations of services or products, or getting funds from businesses as Sponsors, is highly encouraged. The form to use is included in this packet.

Registration Set-Up

- TSSUS will set up an online registration page on the TSSUS website to register folks and collect fees and donations from participants.
- Registration should begin at least 60 days prior to your event. Specific details about registration will be described during the process
- TSSUS will send email announcements to those in our database that are in your state to advertise the walk, and to provide registration information. You will have an opportunity to send the online registration information to your family and friends and encourage others to share the registration information.
- There is no fee to attend/register for the walk. There is an option to purchase a walk shirt for a fee during registration.

Collecting Funds

The registration site also includes an opportunity for walkers and non-walkers to make a donation to TSSUS and/or participate in social fundraising-- each walk participant creates their own fundraising page with their personal information and shares it with their circle of friends and family. All donations can be designated in honor or memory of someone.

People may want to support your fundraising efforts with cash donations, especially the day of the walk. All cash donations must be converted to a money order or cashier's check (for security) and mailed to TSSUS.

Personal or business checks should be made out to TSSUS. Write the purpose (registration, sales), location and date of the walk on the memo line. All donations or sponsorships made online or by check written to TSSUS are tax deductible and will be acknowledged upon receipt. Please include the Sponsor/In-Kind Donation form for each occurrence.

All checks must be sent to TSSUS within 30 days of the date written on the check (donors like timely deposits).

Sharing Your Story

The system TSSUS uses for registration offers a way for every walker to share their own story with friends and family. Sharing stories raises awareness of TS, and it can also raise funds for TSSUS when using your story to ask those friends and family to support you by making a small donation. The feature is called Social Fundraising and everyone who registers for the walk will be invited to make a page to fundraise. It's a perfect way to raise additional funds beyond registration fees.

Advertising the walk in your local community (optional)

- TSSUS can personalize a walk flyer so you can invite participants and raise awareness of TS. Please ask for the flyer if you want one.
- Contact local media to submit press release or invite a reporter attend your event.
- Post flyers at libraries, hospitals, community centers, etc. (with permission.)
- Partner with other community organizations to recruit more participants, such as high school or college clubs and organizations, and other local nonprofit groups.
- Share your walk information on Facebook and Twitter and encourage others to do the same.
- Send periodic reminders to members, family, and friends.

Six-Eight Weeks before the Walk

The walk registration site opens and an email is sent to people in our database who live in your state. Working with your team to get details of your event planned as far in advance as possible helps you enjoy the process and problem solve as things come up. This is the time to get sponsors and in-kind donations for the extras you have envisioned. Decide on those fun activities, get sponsors and promote the walk and TS accordingly. Be sure to get approval for all expenses you want reimbursed.

One Week before the Walk

You will receive a “Chasing Butterflies Walk Box” from TSSUS that includes the items you need based on your online registration information:

- A print out of the walk registration details: including the names of registered walkers, donors and those who ordered sales items.
- A photo opt-out release form for attendees who do not want their photos used by TSSUS.
- Sign-in table items; a tablecloth, table runner, banner, and donation envelopes.

The Week of the Walk

- Be prepared to recognize your supporters either verbally or on a poster board, etc.
- Don't forget to designate someone to take lots of photos!

The Day of the Walk

- Arrive early to set up before your walk participants arrive, and greet everyone with a big smile!
- Set up a check-in table. You may need to bring a table with you. Check ahead of time with the walk venue. Use the table covering, table runner, banner, TS brochures and the other items sent for the walk.
- Organize lines for those who registered online and those walk-up registrants.
- Thank and recognize all participants, sponsors and media representatives, as well as inform the participants about TSSUS. Use the provided outline as your guide when talking.

After the Walk

- Complete the Walk Summary Form provided to you.
- Submit the following to TSSUS within 30 days of the walk: Summary Form, money order of cash donations, check donations, the tablecloth, banner, and any other TSSUS items.
- Send a written thank you to those who helped make your walk a success.

We hope these guidelines give you an idea of the expectations and the opportunities for hosting a walk. Please contact the office if you have questions. We are here to help make your walk successful.



The Turner Syndrome Society is grateful for your consideration of sponsoring an aspect of our community Walk for Turner Syndrome.

Sponsorship amounts are tax-deductible
 TSSUS is a U.S. 501c3 non-profit organization EIN 41-1596910

Local Walk Event Sponsorship Opportunities

- | | |
|--|----------------------|
| 1. Registration Area Sponsor | minimum \$250 |
| 2. Beverage/Refreshment Sponsor | minimum \$200 |
| 3. Activity/Entertainment Sponsor | minimum \$150 |

Please select methods you wish to be recognized:

- Logo displayed at the registration table
- Recognition during the welcoming
- Company name/logo displayed on the walk registration webpage (please email logo at least 2 weeks before event)
- Promotional items for each walk attendee- no attendance (please provide to walk coordinator at least 1 week before event)
- Exhibit and offer promotional items (must bring own table/chairs)

Sponsorship Level Requested: _____

Company Name: _____ Website: _____

Address: _____ Phone: _____

Contact Name: _____ Email: _____

For more information, please contact your local Walk Coordinator or Deborah Rios at the national office. In-Kind Sponsors will receive recognition during the welcoming.

In-Kind Sponsor	Donation/Product	Value of Product
<input type="checkbox"/> In-Kind Sponsor		\$
<input type="checkbox"/> In-Kind Sponsor		\$

Please email Becky@turnersyndrome.org sponsor information and high resolution logo and contribution to complete the process.

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Outline for Day of Walk: Welcome

Please use this outline when you prepare what you will say to the crowd at the beginning of your Chasing Butterflies Walk. This list is not exhaustive and can be modified to fit your needs and event.

- Thank everyone for attending.
- Recognize any business who gave money, services or goods to the walk.
- Recognize any media representatives present.
- Thank everyone who raised money for TSSUS through social fundraising online.
- Thank everyone who donated money on the day of the walk.

- Inform the crowd about the Turner Syndrome Society:
 - The mission of the Society is: Advancing knowledge, facilitating research, and supporting all those touched by Turner syndrome.
 - The website is turnersyndrome.org
 - Educational and awareness resources are available on the website
 - The goals of every Walk held across the nation are:
 1. To raise awareness of TS in the general public
 2. To build a support network of TS in the local community and distribute/inform the TS community about helpful resources.
 3. And to raise funds for programs at TSSUS that help promote research and support those touched by TS.

- Finally, describe the walk route and procedures and tell everyone to *have fun!!*