



WALKER PARTICIPATION PACKET

- Make a difference in ONE MILLION lives
- Provide HOPE to individuals and families that live with TSC everyday
- Have a great time with family and friends!

For more information contact:

Dee Triemer
Community Outreach Manager
Office: (800) 225-6872
Fax: (678) 546-0883
dtriemer@tsalliance.org

WITH A CURE. WHERE OUR STORY MUST END.

THE DISEASE WE'RE UP AGAINST IS FORMIDABLE. BUT SO ARE WE.

Our story is not about pity – it's about a stunningly small group of people with sheer determination who have locked arms and devoted their lives to something bigger than themselves: finding better treatments, and ultimately a cure, for tuberous sclerosis complex.

In 1974, four mothers of children with tuberous sclerosis complex (TSC), having nowhere else to turn but each other, established the Tuberous Sclerosis Alliance (TS Alliance). Their goals were unmistakable: to provide fellowship, generate awareness, pursue more knowledge and provide hope to those that shared the common bond of facing the daily challenges of TSC.

Since then our mission has expanded.

The TS Alliance is committed to finding a cure for TSC while improving the lives of those affected – 1) by developing programs, support services and resource information; 2) by stimulating and sponsoring research; and 3) by creating and implementing public and professional education programs designed to heighten awareness of the disease.

Today, we serve more than 20,000 constituents, sponsor more than 30 Community Alliances nationwide, and receive an average of 1.2 million visits to the Web site monthly.

Tuberous Sclerosis complex is a genetic disorder that causes tumors to form in many different organs, primarily the brain, eyes, heart, kidneys, skin and lungs.

There is no cure.

What so distinct about TSC is that it affects some people more severely, and others so mildly that it often goes undiagnosed. Some people with TSC, for example, are sentenced to a lifetime of seizures, intellectual disabilities and autism. Other people with TSC, meanwhile, are able to live healthy, totally independent lives. It is this not knowing when, how and what to extent the disease will manifest that is so onerous for so many.

Nearly 1 million people worldwide are known to have TSC, with approximately 50,000 in the United States. At least two children born each day in the United States will have tuberous sclerosis complex. While many cases go undiagnosed due to the obscurity of the disease and the mild form of symptoms may take in some people, TSC is as common as ALS (Lou Gehrig's Disease) or cystic fibrosis.

WE'RE FIGHTING FOR THE CURE THAT COULD LEAD TO MORE CURES.

The brain, eyes, heart, kidneys, lungs and skin. Even the adrenal gland, liver, ovaries and pancreas. So many vital organs can be affected – and too often, devastated – by tuberous sclerosis complex.

TSC is a lynchpin disease.

Insights into TSC can provide insights into other diseases. And vice versa. Discoveries in TSC can lead to discoveries in other diseases. And vice versa. New treatments in TSC can lead to new treatments in other diseases. And vice versa.

Bottom line?

Every minute and every dollar spent finding treatments and cures for TSC could bring about quantum leaps forward in treatments and cures for autism, epilepsy and cancer.

WE'VE COME FAR TOGETHER.

WE'LL GO EVEN FARTHER WITH YOU.

The TS Alliance is just that: an alliance – of those who have the disease, and those who have a family member or friend with the disease, of those who are caring for or treating someone with the disease, of those who are trying to find new treatments and a cure for the disease. Simply put – the TS Alliance is powered by people – people from all walks of life, people from all over the country, people just like you.



What can you do to help: Make a difference today by strengthening your commitment to the Step Forward to Cure Tuberos Sclerosis Complex movement, the TS Alliance's largest national event, organized in more than 30 communities across the United States. This event, as you know, offers the opportunity to make an impact on the lives of those living with TSC as well as research into cures for other diseases like epilepsy, autism and cancer. It provides an excellent marketing vehicle for a national sponsor on a local level targeting a mass, consumer-based audience and offers opportunities for awareness, cause-related marketing and enhanced employee relations. We are so grateful for your past partnership and cherish the opportunity to enhance our relationship in the future.

The Step Forward walkathon campaign first launched in 2002, raising \$25,000 in new revenue for the TS Alliance. In fiscal year 2009, twenty-eight communities hosted walks and raised \$1 million. This year, we want to expand to 35 communities and broaden the awareness of TSC through targeted national sponsorships with family-friendly companies, such as Lids, to increase funds for research and community educational and advocacy support.



HOW TO GET STARTED

Step 1: Register

Simply register online at www.stepforwardtocurets.org to join a walk near you. From here you will register for the walk and have the availability to create your own online fundraising page so you can form a team and begin collecting donations!

Step 2: Set a personal goal

There is no minimum requirement or registration fee to participate, but the TS Alliance encourages everyone to set a fundraising goal of \$100 or more. We welcome donations of ALL sizes.

Step 3: Collect your pledges

This is a pre-paid walk. All participants are asked to bring their collected donations on walk day. Make checks payable to the TS Alliance. Be sure to follow up with your donors prior to the walk.

Step 4: Step Forward and Walk!

Simply check in at the registration table on walk day to turn in your donations and review a report of your online donations. Then enjoy your walk and wrap-up party!

PRIZE STRUCTURE

As a THANK YOU to our participants, and as a way to encourage them to fundraise, we offer the following prize structure.

Fundraising Incentive Prize Levels

1. \$100 +
2. \$500-\$999
3. \$1,000-\$2,999
4. \$3,000 and up
5. \$10,000 and up

**Prizes based on the amount of money turned in by walkers on event day. Prizes are not cumulative. You may choose to donate your prize back to the TS Alliance. To see what the prizes are please go to www.stepforwardtocurets.org*

FUNDRAISING IDEAS

8 SIMPLE WAYS TO RAISE \$1,000

Step 1 - Start by donating \$25 to your fundraising page

Step 2 - Ask 4 family members for \$50 each

Step 3 - Ask 10 friends to donate \$20 each

Step 4 - Ask 5 co-workers to donate \$20 each

Step 5 - Ask 5 neighbors to donate \$20 each

Step 6 - Ask 10 people from your gym to donate \$20 each

Step 7 - Ask 5 businesses for a donation of \$25

Step 8 - Ask your boss for a \$50 company donation

DONATION ACKNOWLEDGEMENT

The TS Alliance provides you with receipts for acknowledging donations of \$249 or below. For donations \$250 and up, the TS Alliance will send an acknowledgment within six weeks of receipt. All donations are tax-deductible to the fullest extent of the law. A page of receipts is provided on the next page of this walker participant packet.

SEND THE FOLLOWING SAMPLE EMAIL

Dear Family, Friends, Colleagues and Co-Workers,

Please consider supporting my son/daughter's _____ team as we search for "The Cure That Will Lead To More Cures". **Any amount** truly helps. If you would like to join us walking this year, please look for information on the website linked below or feel free to email me for information...we would love to have you!

We choose to fight, not only for _____, but for the 1 in 6000 kids like her born with TSC every day...50,000 in the U.S...over 1 million worldwide. TSC is more common than Lou Gehrig's disease and Cystic Fibrosis, but you've never heard of it. And there is no cureyet!



Like dominoes, curing TSC will lead to cures for many other diseases.

Ours is a story of determination. Our stunningly small group of parents, through sheer will and passion, have brought this disease to the brink of a breakthrough. We are joined in our fight by aunts and uncles, brothers and sisters, grandparents and friends, co-workers and colleagues. **We're asking you to join us in the fight to find a cure!** Please support families like ours who have refused to give up, refused to take no for an answer, even when faced with the daily challenges of seizures, autism, ADHD, kidney lesions, developmental delay and mental retardation, facial disfiguration, anxiety, behavioral problems, and medical complications.

Every dollar spent finding cures and treatments for Tuberos Sclerosis can bring about quantum leaps forward in the cures for autism, epilepsy and cancer.

We're making HUGE strides in finding a cure for TSC. Here's what we know now that we didn't know just two short years ago: TSC is what's called a "linchpin" disease. The genetic pathway involved in TSC is the same pathway affecting over a dozen major diseases and disorders, including autism, epilepsy, cancer, and obesity. We've got a long way to go, but recent clinical trials of a new drug actually show the symptoms of autism disappearing in mice. We're in a race against time and our resources are strained beyond their limits!

The Tuberos Sclerosis Alliance is the only organization able to rally the financial resources, the research, the partnerships, and the sheer will of TSC-affected families to break the back of this "linchpin" disease.

On _____, we are holding a major fundraising "Step Forward to Cure TSC" in _____. Please join our fight by supporting Ashley's Angels Team and helping to break the back of this horrific disorder. You can make donations securely at: *(add your Firstgiving fundraising page here)*

_____ didn't choose to be born with
Tuberos Sclerosis Complex.....it chose her!

FUNDRAISING IDEAS

EVERYDAY

People can't donate if they don't know you are walking! Talk about the Step Forward to Cure TSC Walk with everyone you come in contact with. Talk to your grocer, doctor, nurses, dentist, etc. Ask them if they would be willing to support your efforts.

Be a guest bartender. Ask your local bar if they'll allow you to be a guest bartender for a night, or even for a few hours on a Saturday afternoon. Send out an Evite, inviting everyone you know to join you there for a drink, and ask them to invite everyone they know. Create a sign to place on the bar or a flyer that reads, "All tips collected tonight will go directly to Joe Walker, who's walking to raise money for people struggling with TSC." When people see the sign, they may be willing to dig a little deeper in their pocket!

Ask your favorite restaurant to help you fundraise. Is there a local restaurant that you frequent? Are you friendly with any restaurateurs? Ask the owners if they will donate a portion of one evening's proceeds to your fundraising total. Then make flyers with the information, create an Evite, and invite everyone you know to dine there on this evening. You'll bring in more business to the restaurant and more money to your fundraising total.

Auction off your skills or trade your services for a donation. Are you a trained massage therapist? Can you organize a closet like no one else? What about cleaning house or re-vamping someone's resume? You can even be the "designated driver" for your friends for a night out on the town. Let people know that you're willing to trade your services for a donation. Set your price high – it's for a good cause!

RAISE MONEY ON THE JOB

Include Step Forward to Cure TSC Walk information as part of your e-mail automatic signature. Include a link to your Step Forward to Cure TSC Walk Web page in your signature. Each time you send a message, the recipient will be provided with a reminder to sponsor you.

Utilize corporate matching gift programs. Many employers will match the charitable donations made by their employees. You may be able to double every donation you get!

Organize "Dress Down Days" at work. Ask management if you can have Dress Down Days to benefit your team at work. Charge people \$5 to wear jeans to work on Fridays or any other specified day. This is a quick and easy way to raise big bucks. Everyone wants to be casual at work; help people fulfill their dreams and contribute to a great cause.

Sell goodies to your officemates. Pick up bulk packages of the most sought-after sweets and set up an "on your honor" snack area near the photocopier machine. Charge \$1 per item.

Collect loose change. Everybody has a stash of loose change in a cup or jar just sitting around. Ask everyone to donate theirs toward your goal. You will be surprised how quickly it adds up.

Fundraising thermometer. Make a poster with a thermometer, your goal being the top, and fill it in as you raise money. If you did the Step Forward to Cure TSC Walk last year, hang up photos or awards. Get creative!

FUNDRAISING EVENTS

Bake Sale. Bake sales are a sure fire way to raise money. Simply make some of your very best cookies, cupcakes, or pies. Have your co-workers and friends get involved, especially those that can't sponsor you financially. Advertise the sale and then watch the profits come in.

Karaoke Night. Sell tickets for an evening of awful singing at a local bar or at home. Get people to donate money to stop their friends from singing or have a singing contest. Charge an entry fee and have proceeds from the ticket sales go to your fundraising total.

Benefit Concerts/Gigs. If you know a rock band, barn dance caller, jazz group, DJ, or string quartet, ask them if they will do a benefit evening for the Step Forward to Cure TSC Walk at a local club or coffeehouse.

Feet Decorating. Hold a good, old-fashioned decorating at your office. Make cut-outs of feet and charge coworkers to decorate their colleagues' offices or cubicles. Charge \$1 per foot. Tape the cut-outs throughout the area. The bigger the area covered, the better!

IDEAS OF THE MONTH

January

Chili Cook Off

It's cold outside, so warm up with a bowl of chili. Gather a couple of your friends who make a mean bowl of chili, and hold a competition for the best bowl. Guests will pay to taste and all the proceeds go to your Step Forward to Cure TSC Walk totals.

February

Valentine's Day

The tradition on February 14 is to shower candy, gifts, and flowers on loved ones, all in the name of St. Valentine. Share the love in the name of Step Forward to Cure TSC Walk to benefit people struggling with TSC. Make "Sponsor Me" Valentine's. Decorate personalized Valentine's cards with information about why you're participating in Step Forward to Cure TSC Walk, your goal, and instructions to sponsor you ("Go to www.firstgiving.com/tsalliance click "Sponsor a Walker", and type in my name.")

Throw a chocolate tasting event! This is a creative twist on your traditional wine tasting event, sure to attract a crowd! Best of all, it's family-friendly!

Sell single roses or flower bouquets in your school or workplace. Chocolate roses are a safe gift for non-romantic purposes, and they never go to waste!

Solicit donations. Simply ask people to "have a heart" and donate to your cause. You can give donors a small token, such as heart-shaped candy, in return.

Award Shows

From the Oscars to the Golden Globes to the Grammys, Hollywood is abuzz with award shows this month! Whichever award show you happen to favor, turn it into a fundraiser!

Throw a party on award show night and charge an entrance fee. Make up games to play throughout the night, like "The Red Carpet Best/Worst Dressed". Make a list of some of the stars that will be there and have your guests rate their outfits and announce the best and worst dressed at the end of the night.

Have a "predict the winners" contest! Print out the ballot of one of the awards shows, have people guess the winners and charge \$10 for each ballot entry. Once the winners are announced, give the lucky winner, who guessed the most correctly, half the pot of money raised, and the other half goes to your fundraising efforts!

March

Spring Cleaning: Spring starts on March 20

Clean out your place! Gather up items that you'd be willing to sell, encourage your friends and neighbors to do some spring cleaning as well, and bring their items to your place for a "garage sale". Post signs letting all your customers know that proceeds benefit Step Forward to Cure TSC Walk.

St. Patrick's Day

Candy Jar Guessing Game: Get a decorative jar and fill it with candy (be sure to keep a count of the candy you are putting in). Then, have people donate \$2 to guess the total amount of candy in the jar – with no limit to the number of guesses. The person who comes closest to the actual number wins the candy, and you increase your fundraising total!

Sell Something Green! Help your co-workers and friends get festive. Buy shamrock fabric and make your own headbands or belts. Or sell ready-made St. Patty's Day shamrock headbands and double the price when you sell because your proceeds are going to the Step Forward to Cure TSC Walk! You can also make some green Rice Crispy treats for a bake sale!

April

Rain, Rain, Don't Go Away

April showers brings May flowers. Use the rain to your advantage. On a rainy night (check the forecast in advance so you can plan), have your friends over for dinner. Charge admission and cook something cozy and warm.

May (*TSC Awareness Month*)

National Pickle Week

Have a Step Forward to Cure TSC Pickle sale May 19 to 24. Have your friends, co-workers pickle all sorts of things (cucumbers, artichokes, carrots, asparagus, beets, cabbage, pigs feet, eggs, etc.). Don't like pickles? Have a sale of a dish that you make well. Offer to bring in your very best tuna casserole for lunch at the office; your co-workers will pay for their lunch by sponsoring you.

Carb-Loading Party

The night before the walk, make lots of pasta and invite people over to carb-load for the walkathon. They can sponsor you for a plate of pasta. This is a great opportunity to get excited for the walk, get last minute donations from your procrastinator friends, and get additional donations from friends who might be walking with you.

June

Tennis Round Robin

Organize a round robin game of tennis with friend, neighbors, and co-workers. Collect the entry fees and donate that to your walk fundraising total.

July

Picnic Dinner

Organize a picnic in your community and create a campaign on giving donations for individuals to sponsor you.

August

Back to School Party

Organize a back to school party with your child's school.

September

Labor Day

Take five for TS. Bring your lunch to work one day and donate that \$5 to TS. Tell five friends; ask them to tell five friends, and so on with each person donating their lunch money for one day, or \$5.

October

Oktoberfest

Host a beer and bratwurst party

November

Give Thanks

Give thanks by giving back letter writing campaign!

In-Home Parties

Host a party such as a jewelry party or pampered chef party.

December

Cookies

Have a cookie exchange party/contest.

WALKER SPONSOR FORM

Step Forward to Cure Tuberous Sclerosis Complex®

Use this form to keep track of your sponsors/donors. Be sure to fill out this form completely and bring it along with all of your pre-paid donations to registration on walk day. All contributions are considered tax-deductible. Receipts: Canceled checks serve as a receipt for ANY donation.

WALKER NAME: _____

TEAM LEADER NAME: _____

PERSONAL GOAL: _____ TOTAL TURNED ON WALK DAY: _____

Each walker is asked to raise a minimum of \$100 in pre-paid donations which should be turned in at registration the day of the walk.

WALK SPONSORS

Name	Donation	Collected
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FREQUENTLY ASKED QUESTIONS

Q: Does everyone have to register?

A: Everyone over the age of 2 has to register for the Walk. If you have your children under the age of 18 with you, simply fill in their name under your signature on the registration envelope, that is it, they are ready! Each walker 18 years or older must complete and sign their own registration envelope.

Q: What if it rains?

A: The event will happen rain or shine. Please dress accordingly.

Q: Can I bring my dog to the walk?

A: Please use your best judgment regarding your pet's ability to handle crowds. Dogs that are uncomfortable with children and crowds should not attend the Walk. Please be sensitive to the fact that many of our children are very fearful of animals.

Q: What activities will be taking place at the walk?

A: We will have children's activities, music, snacks and more, in addition to the walk! Bring the whole family and enjoy!

Q: Is there a rain date?

A: No. The event will take place rain or shine, so be sure to join us on Walk day to turn in your donations and enjoy Walk Day. Come prepared with raincoats and umbrellas if it's raining on Walk day!

Q: Is there a fee to walk, and can I bring friends and family to the walk?

A: There is no fee to attend the walk. The Walk raises money to support research, family services, advocacy and awareness. Any donation you can give, no matter what size, makes a huge impact. As a walker, you are encouraged to ask your friends and family to sponsor your walk efforts. Walkers who raise \$100 or more before the walk either online or through donations brought to the walk, will earn a t-shirt on Walk Day. Family and friends are welcome to join the walk!

Q: How can I/ my family members earn a walk t-shirt?

A: Walkers who raise \$100 or more before the walk through online donations and/or donations brought to the walk, will earn a t-shirt on Walk Day. If your minor children are with you on walk day and you have them listed on the registration envelope, and have raised at least \$100 per child, they will also receive a walk tee shirt. For example, for a family of four that are all present on walk day, you would need two registration envelopes (one per adult) and on one envelope you may list the minor children under your signature. If you raised at least \$400, each family member would then qualify for a tee shirt.

Thank you for Stepping Forward to Cure TSC!