



# Fundraiser Toolkit

A GUIDE FOR HOW YOU CAN  
FUNDRAISE TO SUPPORT TBCK  
WARRIORS

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# Organizational Pillars



## **Our Mission:**

The mission of The TBCK Foundation is dedicated to serving families impacted by TBCK Syndrome through accelerating patient-led research, advocacy, education, and a dynamic system of support.

## **Our Vision:**

Our vision is a relentless pursuit to help every patient diagnosed with TBCK Syndrome find the best quality of life.

## **Our Values:**

Our commitment is to diversity, equity, and inclusion. We continue to elevate voices of diversity, people with disabilities, women, LGBTQ+ community, and marginalized groups to reflect a wide range of vantage points that bring insight to our efforts.

The TBCK Foundation values respect, integrity, solutions-based approaches, and collaboration and seeks to foster a welcoming and productive environment that uplifts our community and accelerates our mission forward.

## **Our DEI Statement:**

The TBCK Foundation is a 501(c)(3), nonpartisan organization that proudly prioritizes diversity. We are committed to building an inclusive community, where all individuals and groups belong. The TBCK Foundation intentionally supports the empowerment of women, people from diverse backgrounds, the LGBTQ+ community, people with disabilities, and groups that have been historically marginalized. We believe we are stronger together. Together we are better equipped and informed to build a more just, equitable world without the devastation TBCK Syndrome causes. The global TBCK community brings together families, healthcare providers, advocates, researchers, and diverse stakeholders to improve lives impacted by TBCK Syndrome.



# Overview

*Ready, Set, Go!*

## What Is The TBCK Foundation?

The TBCK Foundation is a rare disease non-profit founded to support research, advocate, and educate for those kids impacted by TBCK syndrome, a rare neuro-genetic disease that causes severe epilepsy, intellectual disability, and developmental differences. With around 100 cases worldwide, TBCK Syndrome is a very rare disease. With limited active research and no resources specific to TBCK syndrome, Nikki Stusick and Turner Binkley founded The TBCK Foundation in 2019 inspired by their son, Theo. Part of our mission is accelerating research to seek a better understanding into TBCK Syndrome, which remains under-researched with limited understanding of the disease. Our other focus is supporting TBCK families and other "rare" families as they navigate through the world of different abilities and disability. The TBCK Foundation is committed to educating and advocating for change for more inclusion, acceptance, and working to demystify disability.

## Why Fundraise For The TBCK Foundation?

Thank you for being here and for being up for fundraising for The TBCK Foundation (TTF). Because of your generosity, each dollar raised helps TTF reach for the essential goal of funding treatments for our kids and our goals of better supporting and advocating for our families. Founded in 2019, researching TBCK is the primary focus of The TBCK Foundation. We were founded to help advance research. Right now there are no treatments and limited active research. That is where donations really count. They can turn potential research of TBCK into a reality. Beyond advancing research, TTF is dedicated to advocacy, education, and family support for families impacted by TBCK Syndrome.

## How Does The TBCK Foundation Use Donations?

The TBCK Foundation uses donations to carry out our mission and to support families through our work. We have some time-limited grant funding, so individual, major gifts, and all donations make an impact.

## How Can This Toolkit Help?

Our hope is that this toolkit will serve as a guide as you make plans to host an event to fundraise for The TBCK Foundation. There are a million-in-one ways to find ways to support TTF and here is just a guide to help you get started! We can't wait to see what you come up with!



# Getting Started

## You Have An Idea For A Fundraiser, Now What?

*It is our pleasure to help assist with your event!*

*Here are the specific things we can help with:*

- Consulting - from brainstorming ideas to giving our insights, we can help you move your ideas forward. Perhaps we can even put you in touch with anyone who may have already organized an event like the one you're planning.
- Approved use of our logo, when appropriate
- The TBCK Foundation branded materials
- To validate the authenticity of the event and its organizers, a letter of authorization
- Tax ID number for donation purposes only
- Help with writing letters, emails, press releases, and other promotional material
- Your own personalized fundraising page on our website:  
[www.tbckfoundation.org/events/YOUR EVENT!](http://www.tbckfoundation.org/events/YOUR EVENT!)





# Getting Planning

## TOP 9 CHECKLIST

1. Form a planning committee. It could just be your family or friends or people dedicated to supporting kids like ours!
2. Brainstorm. There are millions of possibilities- have your committee determine the best one for your group!
3. Target your audience. Who is likely to come? What group of people would be likely to participate?
4. Develop a budget. What are your expenses? What in-kind products and services may be possible?
5. Schedule the event. Aim for a time and date to get the most participants! Checking local calendars/events to avoid overlap.
6. Let The TBCK Foundation know! When you let us know, we can get the word out on your event on our website and social media!
7. Make an event timeline. What needs to be done? When does it need to be done? Lots of events out there already have example timelines and checklists, don't recreate the wheel if you don't need to!
8. Congrats you get to send off the funds! Collect all funds. We ask that all funds be forwarded to The TBCK Foundation within 30 days following the event. Contact us for shipping information.
9. Thank you, Thank you! By saying thank you, all participants, sponsors, and donors feel recognized. Say thank you! It might be a letter, email, a phone call, or another way. We are so thankful for our supporters and showing that we care about their support helps to build a relationship and encourages their good will!



# Event Ideas!

## The Fun Part: What Should You Do?!

***There are so many ways you can make a difference. Here are some possible events to encourage your creativity and planning!***

Restaurant Match • Car Show • Ornament Sale • Office Jeans Day  
• Pie Smash • Potluck • Game Night • Cook Off • Bike-A-Thon •  
Variety Show • Car Show • Luncheon • Garage Sale • Holiday  
Gatherings • Fun Run • Read-A-Thon • Flea Market • Fashion  
Show • Auction • Music Concert • Scavenger Hunt • Walk-A-  
Thon • Talent Competition • School Fundraiser • Super Bowl  
Party • Sports Tournament • Boat Racing • Church Fundraiser •  
Golf Outing • Black-Tie Event • Dance-A-Thon • Dine Out for a  
Cause • Restaurant or Retail Promotion • Toy Drive with  
Monetary Donation • Bake Sale • Craft Sales • Wishing Well •  
Trivia • Car Wash • Coin Drive • Movie Night • Lemonade Stand •  
Picture with Santa, Easter Bunny, etc. • Art Fair • Cooking Class





# Getting The Word Out!

**Planning Takes Months, Be Sure To Plan Well In Advance!**

## ***Create a timeline to maximize publicity.***

- ✓ 3-4 months before the event identify your target audience
- ✓ 4-6 weeks before the event distribute media materials
- ✓ 2 weeks before the event make follow-up calls + send emails
- ✓ 1-2 days before the event send a media alert to news

*Suggested language:* The following is a simple description of The TBCK Foundation .

TBCK syndrome is an inherited, rare, neurogenetic disease with currently no treatment or cure. All identified patients are children or young people. The disease causes epilepsy, intellectual disability, severe hypotonia, and medical complexity. There are nearly 60 diagnosed children worldwide living with TBCK syndrome.

## **Social Media!**

*Effective social media can make a big impact before and after your event!*

- Tell why you have created this event. Be specific about event details, your goal, and the difference it makes for The TBCK Foundation.
- Always include a link to your fundraising page!
- Post consistently! Share updates before, during, and after your event.
- Tag us in your photos on Facebook and Instagram (@tbckfoundation)

## **Photos At The Event!**

- Write out a photo wish list in advance to make sure you get photos of everything and everyone you want.
- Take candid and close-up shots that capture the different aspects of your fundraiser.
- Include kids in the photos, if applicable. Use our photo release form.
- Take pictures of your corporate sponsors, if applicable.
- Photos with 1-3 people only are the best for publicity.
- Post the photos to your social media accounts



# You Nailed It! How To Wrap Up!

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*How's it feel to be a world changer?!*

## What To Do After Your Fundraiser:

- Send in **donation/proceeds**, contact us for address information! (No cash, check only!)
- Include a short note explaining your fundraiser. Email a list of those who donated to us. (We love thanking your donors ourselves and keeping in touch with them about updates!)
- Send some **photos** from the event! We love seeing impact at work!
- Nothing shows gratitude louder than a big **THANK YOU!** By sending notes, emails, or making a phone call to all participants and supporters in your event shows your (and our) appreciation!
- You are a pro now! You can start thinking of your **next fundraiser!** What worked well? What needs to change? Taking notes and keep track of improvements and what to expand is helpful for future events and ways to reach even more people!



# FAQs



## **Can I use The TBCK Foundation's tax exemption number?**

Because The TBCK Foundation is not hosting your event, it is considered a third-party event. For this reason, you will not be able to use the Foundation's IRS 501(c)(3) charitable classification, federal tax ID number or tax-exempt certificate. However, you may use the tax ID number for donation purposes only. Please email us!

## **Can you help me get a permit or insurance for my event?**

The organization and execution of the event is the responsibility of its event organizer. You must obtain all necessary permits or licenses. The Foundation cannot provide insurance for third-party events. The event organizer is responsible for obtaining insurance for the event, if needed. Most local insurance companies can assist with this.

## **What can I give people who made donations for tax purposes?**

The TBCK Foundation third-party event organizers cannot use The Foundation's tax exemption status in conjunction with the event. However, The Foundation can provide an authorization letter confirming the organizer's intent to raise funds for The TBCK Foundation. In addition, we will send an acknowledgement letter.

## **Will each of my donors get a receipt?**

If you provide name and address, or email address, for donors or sponsors, The TBCK Foundation will send them a personal thank you from the Foundation, which will serve as a receipt.

## **Can someone from The TBCK Foundation attend or help me plan our event?**

Depending on the event location and date- this could be possible! We are happy to provide guidance for your event, but logistics may prevent us from attending.



# Fundraiser Guidelines!



Because of non-profit, tax-exempt status, we must be diligent to be compliant with the law. There is something called a “Third-Party Event” which is defined as any fundraising activity conducted by a group or individual that is not employed by The TBCK Foundation, where The TBCK Foundation has no fiduciary responsibility and little or no staff involvement in its execution. These policies pertain to all events or activities benefiting The TBCK Foundation that are organized and executed by third parties.

## **Organizer Responsibilities**

- All expenses are the responsibility of the event organizer. The TBCK Foundation is not responsible for any expenses incurred for a third-party fundraising activity, and will not advance funds or reimburse expenses unless approved in advance by the Board of Directors. We recommend finding event sponsors or charging a registration fee to help cover expenses. You may not purchase goods or services under The TBCK Foundation's name, and The TBCK Foundation's sales tax-exemption (on purchase) cannot be extended to any third-party event of fundraising effort.
- The event organizer is responsible for the planning and execution of the event including safety precautions and adherence to applicable laws. As the beneficiary of a fundraising event, The TBCK Foundation does not accept or assume any liability associated with the event, including, but not limited to, any injuries sustained by event volunteers or participants during the event. The event organizer will indemnify, defend, and hold harmless The TBCK Foundation its directors, officers, and employees from any and all claims that may arise out of or relate to such event.
- The event organizer is responsible for obtaining all applicable permits or licenses, including, but not limited to, alcohol, solicitation, and sales tax licenses.

## **Promotion and Publicity**

- All third-party events must be publicized and conducted in a manner that makes it clear that The TBCK Foundation is the beneficiary, not the sponsor or host of the event.
- Promotional materials must clearly state that the event is raising funds that will benefit The TBCK Foundation (e.g. “proceeds benefit The TBCK Foundation”)
- Event names may not incorporate the name of The TBCK Foundation. The name may be used in a second clause identifying the relationship of the event with the Foundation, such as “John Doe Gala”, benefitting The TBCK Foundation.”
- All event materials that include The TBCK Foundation's logo, including, but not limited to, advertising, press releases, posters, flyers, t-shirts, and public service announcements, must be reviewed and approved prior to distribution.

## **Financial Policies**

- The event organizer may not keep any portion of the proceeds (beyond real expenses) as profit or compensation.
- The event organizer may not set up a temporary bank account in The TBCK Foundation's name, as this is illegal.
- Donors must be informed that the tax deductible amount of a donation is only the amount that is over and above the value of any goods or services received in exchange for the donation. For example, if a participant pays \$200 to participate in a golf outing, and the value of the outing is \$50, the donation amount is \$150. If a donor pays less than the value of an item, then they will not receive a tax deduction.
- If goods are sold to raise money as part of a fundraising event, it must be made clear to the event participants what percentage of the sale price benefits The TBCK Foundation.



# A Very Special Thank You

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This resource is made possible through the amazing minds behind The Barth Syndrome Foundation. We are so grateful to their team for building this incredible resource for organizations to utilize.

Check out their work here: [www.barthsyndrome.org](http://www.barthsyndrome.org)

