Social Media Guide

Be the TSC cheerleader in your virtual world! Social media is a great way to get your message out, spread awareness about TSC and Step Forward to Cure TSC, and raise money toward your team's fundraising goal by rallying your online community for your cause. Be sure to follow the <u>Step Forward to Cure TSC</u> Facebook page and the TSC Alliance on on <u>Facebook</u>, <u>Instagram</u>, <u>TikTok</u>, <u>X</u> and <u>LinkedIn</u>.

Social Media Basics

Which social media platform to use

 Pick the best platform for you as a participant. Some questions to ask yourself: What platform are you already active on? Where do you have the most followers? Do you have a public account on this platform? Remember: You can always reset your account to private after the event.

What to include when you post on social media

- Photos and videos that show you are STEPPING FORWARD FOR TSC.
- ENGAGE with your audience: ask questions, share their content, give shout-outs to donors and your team members.
- Be yourself and be authentic: tell them WHY you are participating and HOW TSC has impacted your life.

Finish every post with a CALL TO ACTION: Include a link and ask your followers to join your team or donate.





What is a #hashtag?

- A hashtag is a "#" symbol followed by a word or a phrase. If a phrase follows the "#," no spaces are placed between words. No punctuation is used in hashtags, though numbers and emojis are commonly included.
- We encourage you to use these two hashtags to help build awareness for this Step Forward event and the TSC Alliance on each of your posts: #StepForward4TSC, #Step4TSC and #TSCAlliance.
- Here are some more hashtags for across the organization (capitalization is not necessary):
 #stepforward4tsc, #tscalliance, #hopenomatterhowcomplex, #tscstrong, #tuberoussclerosiscomplex
- Make up your own team hashtag too!

Why use hashtags?

• A hashtag is a label for content to categorize it all in one place. It helps others who are interested in a certain topic quickly find content by searching or clicking on the hashtag.

How to post a hashtag on social media

 Posting a hashtag is incredibly easy. All you need to do is create a new post on Facebook, Instagram, X or LinkedIn and include the hashtag somewhere in the post. You can put the hashtag at the beginning of the post, within the text or at the end. Capitalization or location of the hashtag in the post does not matter.

Follow <u>Step Forward to Cure TSC</u> on Facebook and <u>@tscalliance</u> on Facebook, Instagram, X and LinkedIn to see the activity and example posts. Helpful tips for Facebook

Facebook provides tremendous awareness and fundraising opportunities for participants like you, whether by connecting your Step Forward to Cure TSC fundraising page to Facebook, posting your fundraising page link, starting a Facebook Fundraiser or going LIVE to let others know why the TSC Alliance is important to you.

Facebook Basics

- Facebook has no character limit.
- You can summarize a story, mention key points or write longer posts to share your full story.
- Be sure to use your hashtag(s), tag <a>lightstyle and share your location.

Sample Facebook Post

 TSC is a devastating disease that affects (me/someone I love). It is also the leading genetic cause of epilepsy. You can inspire hope in all those affected. Will you donate to my campaign or join my team?
 #StepForward4TSC #TSCAlliance @tscalliance <with link to page>

Facebook Stories

- Use Stories for pictures, short videos, polls and questions!
 - Go to your newsfeed and find the blue+ 'Create story' icon on your profile image or go to your profile and click the '+Add to story' button under your about section.
 - Decide what type of story you would like to share (Text, Selfie, Boomerang or Photos/Videos).
 - Select pictures or videos from your camera roll or tap the camera icon to create your own visual.
 - Click the bottom LEFT Gear icon to change privacy setting to PUBLIC. Then click the 'Share' button.



Instagram is a hugely visual platform, allowing users to upload inspirational images and videos. This is a great opportunity to use images and videos (reels) to help raise awareness about TSC to not only your friends but ALL users.

Instagram Basics

- Images and reels are the focus of Instagram.
- Be a visual storyteller, use photos of you/your family to tell your story.
- Posts can also be longer on Instagram.
- You can use multiple images in one post.
- Make sure to add any links to your bio and to in include hashtag(s) in your post or in the comments.

Sample Instagram Post

• LINK IN BIO! TSC is a devastating disease that affects (me/someone I love). You can inspire hope in all those affected today by supporting @tscalliance. Will you donate to my campaign or join my team? Learn more at the link in my bio! #StepForward4TSC #TSCAlliance

Instagram Stories

- Use Instagram stories to share pictures, videos, stats and other powerful posts.
 - Go to your profile. Find the blue+ 'Add to story' icon on your profile image.
 - Select pictures or videos from your camera roll or tap the camera icon to create your own visual.
 - Add any additional text, graphics, music or other elements to enhance your post.
 - Click "Your stories" and then post.
 - To share a post, go to the post, click the arrow icon under the image, and select 'add to story.'

How to post your own "I STEP FORWARD" sign/image

- Download and print the PDF of the STEP FORWARD sign <u>HERE</u>.
- Fill in the blank with a personal message of why you are participating, who you are supporting or whatever you are feeling!

Examples

- I STEP FORWARD to find a cure!
- I STEP FORWARD to fire up support for (INSERT TEAM NAME)!
- I STEP FORWARD for (NAME of TSC Warrior)!
- I STEP FORWARD because I have hope no matter how complex!

Add an image or video using your phone or tablet with your STEP FORWARD sign. Write a post and include your hashtag(s) #StepForward4TSC and be sure to tag @tscalliance and your location in the caption.

STEP FORWARD to cure TSC*	STEP FORWARD to cure TSC	Noted pharma STEP FORWARD to cure TSC
I STEP FORWARD to	I STEP FORWARD because	I STEP FORWARD for
Hope no matter how complex TM	Hope no matter how complex TM	Hope no matter how complex TM

Example text for your posts

- Tell us why you Step Forward for TSC. Download the sign and post your own today. <add link to sign>
- Will you Step Forward with us? Register today for our 2024 Step Forward to Cure TSC Event. <with link to page>
- <Team Name> needs your help. Donate today. <Add link to team page>

How to post a "I Step Forward" template on Facebook and Instagram Stories

- Download and save the STEP FORWARD FB/IG story template <u>HERE</u> to your photos.
- Fill in the blank by adding text to the template with a personal message of why you are participating, who you are supporting or whatever you are feeling.
- Click the 'Stickers' icon, then click the 'Add image' icon to select an image to overlay on the template.
- Tag the @tscalliance and @stepforwardtocuretsc pages on Facebook.
- Follow the steps for posting on FB/IG stories on page 4 & 5 of this guide.

Examples

- I STEP FORWARD to find a cure!
- I STEP FORWARD to fire up support for (INSERT TEAM NAME)!
- I STEP FORWARD for (NAME of TSC Warrior)!
- I STEP FORWARD because I have hope no matter how complex!



Tip: See the "How to" Video for directions for using the "I Step Forward" template on FB/IG Stories.

Helpful tips for using video on Facebook and Instagram

Video guidance 🗾

- Shoot multiple, short videos that you can use on Instagram Reels or post on Facebook.
- Introduce the whole family (if they are comfortable).
- Show behind-the-scenes/favorite activity/something they are working on as a family.
- Include one specific video telling the viewers why joining/supporting the walk is important to you.

Facebook Live

- Start a new post on Facebook and select 'Live Video.' There is also an option to 'Create Reel' under the Reels section on your profile.
- Give Facebook access to your camera and microphone when prompted.
- Choose your privacy and posting settings.
- Write a compelling description. Include your personal page fundraising link.
- Tag friends, choose your location or add an activity.
- Click the blue 'Go Live' button to start.
- Interact with viewers and commenters.
- Click 'Finish' to end.
- Post your reply and save the video to your camera roll.

How to film your video

- Look for good lighting near a window or outside are good options.
- Please hold your phone upward to record a vertical video.
- Make sure you have a good view of yourself on the screen if doing a selfie.
- Each video should be as close to 30 seconds as possible you can film multiple versions!

Instagram Reels 🧿

- We recommend posting videos to Instagram Reels. You can also go 'Live' on IG.
- Videos should be about 15–30 seconds and filmed vertically. 90 seconds is the max time.
- Posting Instagram Reels allows for the video to be shared in Stories and also has the option of showing up in your Instagram feed.
- Videos can be less-polished, behind-the-scenes and contain real-life content,
- Utilizing this feature more will ultimately help TSC Alliance in the Instagram algorithm overall.



Helpful tips for LinkedIn and X



LinkedIn

- Posts can be longer and are typically geared toward a business audience.
- You can use multiple images in one post.
- Make sure the post includes your hashtag(s) (recommended 3-5) and a call to action with a link.

LinkedIn Examples:

TSC is a devastating disease that affects (me/someone I love). You can inspire hope in all those affected today by supporting @tscalliance. Will you donate to my campaign or join my team? <add link to page> #StepForward4TSC #TSCAlliance

With your STEP FORWARD sign:

Join me in stepping forward for the @TSCAlliance. Download and post your own sign today. <add link to page> #StepForward4TSC #TSCAlliance

Χ

- Keep your message concise.
- Limit hashtags to 1-2 per post.
- Include a clear call to action with a link.
- Avoid writing copy in all-caps.
- Keep a conversational tone.
- Consider using emojis to add emotion.

X Examples:

I just registered for Step Forward to Cure TSC where donations support critical TSC research that will lead to new treatments. Will you donate to my campaign or join my team? <add link to page> #StepForward4TSC @tscalliance

With your STEP FORWARD sign:

Will you Step Forward for the @TSCAlliance? Join or Donate Today. <add link to page> #StepForward4TSC #TSCAlliance

Social Media Post Examples

Alexandra Dahlgren is with Kelsey Moffitt-Carney and 14 others

We are immensely grateful to everyone that came to #Stepforward4TSC with us yesterday. You made the day memorable and special in so many ways and we wouldn't be here today without you by our side. From loving our kids, to late night texts when the weight of it all seems to much. to just the every day get together that bring us joy, thank you for your support. You have weathered the ups and downs of TSC with us, let me cry when when we got the call from school that an ambulanc... See more

OB Lauren Shores Shillinger, Rob Grandia and 39 others

Bridgett Claxton April 12 · 🕲

It is #WalkWednesdayso here's a pic of three #tscwarriors

....

please help us raise money for better treatments & a cure for #tsc so kids like Logan, Nell, and Jude don't have to worry about seizures, tumors growing in their major organs, yearly sedated MRIs. & frequent doctor visits any more

Please join #TeamJude or donate if you're able! Thank you!! You are appreciated! datsc #cureTsc #S



Heather Lens is with Kirsten Swain and 7 others.

610 May 14, 2022 - 🕅

tsc with our OK TSC family! We had a great morning at the gathering place the family I never wanted but so grateful to have!! We will give everything but up!! #cure

Bridgett Claxton is with Sydney Turner and 11 others.

without the love and support from our family, f... See more

It was a gorgeous day today for our #StepForward4TSC fundraising walk!! Thank you to everyone

So grateful for our national sponsors and @bwwings @wegmans and *everyone* who supports

TeamJude - not only those who live close enough to join in person, but those who donated &

Jude is a special kid who brings smiles wherever he goes. We wouldn't be where we are today

.....

.....

sent their lovel!

May 13 . @

who helped make today such a success!







Brittani Fullmer Rich is with Stephanie Jensen Van Beekum and Brandon Rich. 44 May 22 . @

Step Forward To Cure Tuberous Sclerosis Complex 2023. I could not have pulled this off this year without such an amazing co-chair @stephanie.vanbeekum, Brandon, and of course so much family support. Sometimes I question why I do this, (and I know Brandon questions me even more (a) but then we are there. surrounded by other TSC families and I have my answer. If I can help spread awareness, and let even one other TSC family know that they aren't in this... See more







laballew Such a fun morning at the KC #StepForward4TSC walk! Ø. We are so very thankful for those who made it out today, bought shirts or donated! Emmaus is a very loved girl. We walk for hope, for research, and for a brighter future for

those living with TSC.

Alexandra Dahlgren you did such an incredible job. Thank you for all your hard work and dedication to this event!

TSC Alliance TSC Alliance of Greater Kansas City 32w

gg5775 You guys all look amazing and I'm so glad it was a successful event. Love the T-shirt and wish I'd paid attention - I totally would've bought one again this year! Miss you and sending ♥ from VA! 32w 1 like Reply

V Q V Can by bridgett.claxton and 30 others Add a comment...

OD Lauren Shores Shillinger and others

13 cc