



Barth Syndrome
Foundation

Dear Athlete,

Thank you for being part of the BSF community and choosing to make your event about more than a finish line.

Athletic fundraisers hold a special place in the Barth community. Barth syndrome affects the mitochondria, which play a critical role in how the body produces energy. As a result, individuals with Barth can experience significant fatigue and exercise intolerance, making physical activity especially challenging. That connection gives every mile, race, ride, and athletic challenge taken on in support of our community added meaning.

We know that the dedication required to complete an event like this is much more than one moment in time, and we are honored to be part of this with you.

This packet includes:

- Information about Barth syndrome and BSF to help you talk to people about our community and the work you are supporting
- A recommended social media post schedule to let people know you're competing and why you will be raising funds for BSF
- A link to your unique fundraising page
- BSF Athlete Swag Bag
- Supporter Swag Bag for your support team

 *thank you*



About Barth syndrome & the Barth Syndrome Foundation

- Barth syndrome is a rare, X-linked genetic disorder caused by a mutation in the TAZ gene. It mostly affects boys.
- The mutation disrupts mitochondrial energy production, which can cause an enlarged or weakened heart (cardiomyopathy), low white blood cell counts (neutropenia), muscle weakness and severe fatigue, and delayed growth.
- There is no cure. Treatment today is supportive — cardiac care, medication, and physical therapy — but Barth syndrome is now among the small percentage of rare diseases with an approved treatment, a milestone reached through research BSF has funded.
- Founded in 2000, the Barth Syndrome Foundation is the only organization in the world dedicated solely to Barth syndrome. It funds research and provides information, guidance, and emotional support to affected families worldwide.
- A note on accuracy: BSF does not endorse specific drugs, tests, or treatments. When you post, stick to facts drawn from barthsyndrome.org rather than making medical claims of your own.

The first treatment for Barth was approved in September 2025 after tireless efforts from the BSF community. With treatment, Wally spends less time in his wheel chair – and learned that he loves riding his tricycle!



At the 2026 Barth Syndrome Scientific, Medical, and Family Conference, NAME participates in research to understand the effect of Barth and FORZINITY(TM), the only approved therapy, on muscle function.



Barth Syndrome
Foundation

Social Media Starter Kit

This guide gives you a six-week posting schedule — from kickoff through race day and a thank-you week — along with sample captions you can copy, adapt, and make your own. You don't need a marketing background to run a great campaign. You just need consistency, honesty about why you're doing this, and a clear ask.

How to Use This Guide

- Copy any sample caption below and swap in your own event name, goal, and story — bracketed text like [Event Name] marks what to personalize.
- You don't need to hit every post. Pick the ones that fit how you use social media, and stay consistent.
- Adapt captions freely for X, TikTok, or LinkedIn — the themes and facts carry over even if the format changes

Posting Tips

- Tag the foundation so the fundraising team can see, share, and thank you
- Use #BarthSyndrome on every post, and consider a personal event hashtag (e.g., #JessRunsForBSF) so supporters can follow your whole campaign in one place.
- Put your fundraising page link in your bio and in every caption — don't make people hunt for it.
- Photos and short videos outperform text-only posts. Training shots, gear flat-lays, and finish-line moments all work well.
- Post consistently rather than all at once: one feed post per week per this schedule, with two or three Stories in between.
- Thank donors specifically and by name when you can (with their permission). A named thank-you drives more giving than a general one.
- Keep medical claims out of your captions. Link to barthsyndrome.org for anything factual about symptoms, treatment, or research — BSF does not endorse specific drugs or tests.
- Remind followers, once near the end, that BSF is a registered nonprofit and gifts may be tax-deductible — but don't state tax advice yourself; point them to barthsyndrome.org for specifics or reach out to the Fundraising Team at fundraisingteam@barthsyndrome.org.





Barth Syndrome
Foundation

Tag us!



@barthsyndrome

Week Recommended “starter kit” content

-6

Announce your event & goal

Instagram / Facebook

In six weeks, I'm taking on [Event Name] — and I'm running for a reason bigger than the finish line. I'm raising funds for the Barth Syndrome Foundation to support kids and families facing this rare, life-threatening genetic disease. Will you help me reach my goal of \$[amount]? Link in bio. #BarthSyndrome #TeamBSF

Story / Reel: Quick video: “I just signed up to fundraise for @barthsyndrome through [Event Name]. Here's why it matters — more soon.” Sticker link to your fundraising page.

-5

What is Barth syndrome?

Instagram / Facebook

What is Barth syndrome? It's a rare, X-linked genetic disorder that mostly affects boys, caused by a mutation that disrupts how cells produce energy. It can lead to heart problems, muscle weakness, a weakened immune system, and growth delays. There's no cure yet — but @barthsyndrome funds the research working to change that. Learn more at barthsyndrome.org. #BarthSyndrome #RareDisease

Story: Poll sticker: “Had you heard of Barth syndrome before today? Yes / No.” Follow with a swipe-up to barthsyndrome.org.

-4

Share your “why”

Instagram / Facebook

Fill-in template: “Why am I doing this? [Share your connection — a friend, a family member, or simply a cause you believe in]. Every mile I [run/ride/swim] is for families who face Barth syndrome every day. Here's how you can help: [link]. #BarthSyndrome #TeamBSF”

Story / Reel: A photo or short video of you training, with a caption naming one specific person or reason you're fundraising. Personal and specific outperforms general asks.

-3

BSF's mission & impact

Instagram / Facebook

Since 2000, the Barth Syndrome Foundation has been the only organization in the world dedicated solely to Barth syndrome — funding research, supporting families, and pushing for treatments. Barth syndrome is now among the small percentage of rare diseases with an approved treatment, thanks in part to BSF-funded research. Your donation keeps that progress moving. [link] #BarthSyndrome #RareDiseaseResearch

Story: Repost a graphic or quote from @barthsyndrome's own page (with credit) and add: “This is who I'm [running/riding] for.”



Barth Syndrome
Foundation

Tag us!



@barthsyndrome

Week Recommended “starter kit” content

-2

Share your progress

[Instagram / Facebook](#)

Halfway to race day, and [X]% of the way to my fundraising goal – thanks to [number] generous donors! Every dollar helps BSF fund research and support families living with Barth syndrome. Help me close the gap: [link] #BarthSyndrome #TeamBSF

[Story](#)

Thank early donors by name (with permission) or post a simple progress bar graphic showing funds raised vs. goal.

-1

Last call before race day

[Instagram / Facebook](#)

One week until [Event Name]! This is my last full push to hit \$[goal] for the Barth Syndrome Foundation. If you've been meaning to donate, now's the moment – every gift gets BSF closer to better treatments and stronger support for families. [link] #BarthSyndrome #OneWeekToGo

[Story / Reel](#)

Countdown sticker (“7 days to go”) plus a short clip of your final training session or gear flat-lay.

0

Race day

[Instagram / Facebook](#)

Today's the day! Toeing the line at [Event Name] for the Barth Syndrome Foundation. Thank you to everyone who's donated, shared, and cheered me on – this one's for you, and for every family navigating Barth syndrome. #BarthSyndrome #RaceDay

[Live Story](#)

Real-time photos or short clips from the start line, the course, and the finish. Tag @barthsyndrome so the foundation can share and thank supporters too.

+1

Results & gratitude

[Instagram / Facebook](#)

I crossed the finish line at [Event Name] – and thanks to [number] of you, I also crossed my fundraising goal, raising \$[total] for the Barth Syndrome Foundation! Thank you for making this about more than a race. If you haven't donated yet, it's not too late: [link]

#BarthSyndrome #ThankYou

[Story / Personal thank-you](#)

Individually thank major donors via direct message or a tagged shout-out post. A personal note goes further than a public one and builds the relationship for next time.



Email 1 — Announce Your Fundraiser

SUBJECT: I'm taking on [EVENT] for the Barth Syndrome Foundation

Hi [NAME],

On [DATE], I'll be taking on [EVENT], and this time I'm doing it for something bigger than the finish line.

I'm raising funds for the Barth Syndrome Foundation, an organization dedicated to supporting individuals and families affected by Barth syndrome and advancing research for this ultra-rare disease.

Because the Barth community is so small, many people have never heard of Barth syndrome. That's one of the reasons I chose to take this on. Every person who learns about Barth, shares my fundraiser, or makes a gift helps bring more people into the community supporting this work.

My goal is to raise \$[GOAL], and I'd love your help getting there.

[DONATE TO MY FUNDRAISER]

Whether you donate, share my page, or simply follow along as I train, thank you for being part of it.

[ATHLETE NAME]



Email 2 — Mid-Campaign Update

SUBJECT: An update from my [EVENT] training

Hi [NAME],

I'm officially [X weeks/days] away from [EVENT]!

Training has included [PERSONAL UPDATE — longest training run, funny story, difficult workout, milestone, etc.], and I'm getting closer to the starting line.

I'm also [X]% of the way to my \$[GOAL] fundraising goal for the Barth Syndrome Foundation.

One of the things I've learned through this experience is just how small the Barth syndrome community is. That makes every new person we reach especially meaningful.

If you've already donated or shared my fundraiser, thank you. If you'd still like to support me, there's plenty of time:

[SUPPORT MY FUNDRAISER]

I'll keep you posted as race day gets closer!

[ATHLETE NAME]



Email 3 — Results + Thank You

SUBJECT: We did it — thank you

Hi [NAME],

I crossed the finish line!

After [weeks/months] of training, I completed [EVENT] on [DATE]. But the part I'm most proud of is what we accomplished together.

Thanks to [NUMBER] supporters, we raised \$[TOTAL] for the Barth Syndrome Foundation.

Thank you for donating, sharing my fundraiser, sending encouragement, and following along. What started as my personal challenge became an opportunity to introduce more people to Barth syndrome and support a community that means so much to me.

[OPTIONAL: PERSONAL RACE-DAY REFLECTION OR FAVORITE MOMENT]

If you meant to donate but didn't get the chance, my fundraising page is still open:

[FUNDRAISING PAGE]

Thank you for making this about so much more than a finish line.

[ATHLETE NAME]