

Social Media Guidance and Campaign Ideas

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How to Create Your Social Media Fundraiser

Choose Your Platform

Open Facebook or Instagram and select the option to create a nonprofit fundraiser.

Select RARE Foundation

Search for and select the **RARE Foundation** as the benefiting organization.

Set Your Goal and End Date

Choose a fundraising goal and end date.

Personalize Your Story

Personalize the title and description with your connection to the rare disease community.

Choose an Image

Add a personal photo or an approved the RARE Foundation graphic.

Review and Publish

Review your information and publish your fundraiser.

Choose How You Want to Share

Posts and Stories

Share personal updates, approved graphics, rare disease facts, milestones, and donor gratitude throughout your campaign.

Direct Outreach

Send your fundraiser personally to friends, relatives, coworkers, and others who may be interested in supporting your effort.

Central Campaign

Create a dedicated fundraiser where supporters can learn about your connection, donate, follow your progress, and share the fundraiser with others.

Social Media Options

Tag the RARE Foundation and any co-hosts or partners in every post. This pushes your content into their audience's feeds.

Use Hashtags: Pair your main tag #RAREFoundation with 2–3 related hashtags like #RareDisease, #TeamRARE, or #GivingTuesday.

Go Live: A 5-minute live video update can double engagement and spark instant gifts.

Create a “Tap to Give” Story Series: On Instagram, build a 3-slide story: 1) Impact stat, 2) Personal photo, 3) Direct “Give Now” link sticker.

Sample Posts/Captions

Sample Caption 1: Why I'm Fundraising

I'm fundraising for the RARE Foundation because [insert your personal reason or who you're honoring]. 1 in 10 Americans live with a rare disease, yet 93–95% have no FDA-approved treatment. Together, we can change that.
Join me by making a gift today: [Fundraiser Link]

Sample Caption 2: The Power of Small Gifts

Every dollar makes a difference. Whether it's \$5, \$15, or \$50, your gift fuels advocacy for equitable access to diagnoses, treatments, and cures for people living with rare diseases. I'm fundraising in honor of [insert personal story/connection] — will you join me?
Donate here: [Fundraiser Link]

Sample Posts/Captions

Sample Caption 3: Progress Update / Milestone Post

We've already reached [insert % or dollar milestone] of my fundraising goal! I'm so grateful for everyone who has supported this campaign in honor of [insert your personal connection or story]. Let's keep the momentum going! Together we can make rare diseases impossible to ignore.
Give here: [Fundraiser Link]

Sample Caption 4: Mission-Driven

1 in 10 Americans lives with a rare disease, yet most have no treatment or cure. I'm fundraising for the RARE Foundation to ensure patients' voices are heard in Washington and beyond. Every dollar helps move science into action.
Join me today: [Fundraiser Link]

Sample Posts/Captions

Sample Caption 5: Personal Connection

I'm supporting the RARE Foundation because [insert personal reason]. This organization empowers patients and families to advocate for research, policy, and equitable access to care. Will you join me by donating to my fundraiser?
Donate here: [Fundraiser Link]

Sample Caption 6: Urgent / Impact

93–95% of rare diseases have no FDA-approved therapy. That's why I'm raising funds for the RARE Foundation — to help change this reality. Together, we can make rare disease voices impossible to ignore.
Give here: [Fundraiser Link]

Sample Posts/Captions

Sample Caption 7: Final Push (Last 48 Hours)

We're down to the last 48 hours of my fundraiser! Every dollar helps fuel advocacy for rare disease patients who deserve faster diagnoses, treatments, and cures. If you've been waiting for the right time to give, now's the moment.
Donate today: [Fundraiser Link]

Sample Caption 8: Almost There!

I'm so close to reaching my fundraising goal! Your gift in these final hours will help ensure rare disease voices are impossible to ignore. Together, we can finish strong and make a lasting impact. I'm beyond grateful for everyone who has supported my fundraiser — thank you!
Give now: [Fundraiser Link]

Sample Thank You Posts/Captions

Group Gratitude

- Thank you to everyone who has donated so far! Your support means the world to me and to the 30 million Americans living with rare diseases. Together, we're raising awareness, hope, and change.

Personal Spotlight

- Huge thanks to [tag donor(s)] for supporting my fundraiser! Your generosity fuels advocacy for equitable access to diagnoses, treatments, and cures for rare disease patients like [insert personal connection].

Milestone Thank You

- Thanks to your amazing support, we've reached [insert % or dollar milestone]! I'm deeply grateful for every donation, comment, and share! It helps amplify rare disease voices and make them impossible to ignore.

Testimonials

Testimonials are a powerful way to bring your fundraiser to life and make it more personal. By sharing real stories — like those about advocacy journeys, research impact, community connection, or hope for the future — you give your audience something tangible to connect with.

These stories help illustrate why the cause matters, highlight the difference the RARE Foundation makes, and show how support changes lives. Use them in your elevator pitch, emails, social media posts, and fundraising pages to deepen emotional connection, inspire action, and make a bigger impact with your efforts.

Fill In Blank Testimonials

Story Template 1: Advocate / Family Experience

- “When my [child / parent / sibling / loved one / I] was diagnosed with [name of rare disease or ‘a rare disease’], we felt [emotion: lost, overwhelmed, uncertain]. The RARE Foundation gave us [tools / resources / connections / hope] to [advocate in Washington / connect with others / raise awareness / push for change]. That’s why I’m fundraising — to give more families the same [support / voice / hope] that we received.”

Story Template 2: Policy & Research Impact

- “As a [rare disease patient / caregiver / advocate], I’ve seen how long it can take to get a [diagnosis / treatment / care plan]. The RARE Foundation has mobilized advocates like me to push for [legislation / research funding / access to treatments] that speeds up [diagnosis / research / drug development / equity in care]. Your gift helps make that possible, and I’m fundraising to keep that momentum going.”

Fill In Blank Testimonials

Story Template 3: Community & Connection

- “When I first connected with the rare disease community through the RARE Foundation, I realized I wasn’t [alone / invisible / without a voice]. Being able to [share my story / meet others / advocate together] has given me [strength / hope / purpose]. I’m fundraising to help others find the same [community / empowerment / voice] that changed my journey.”

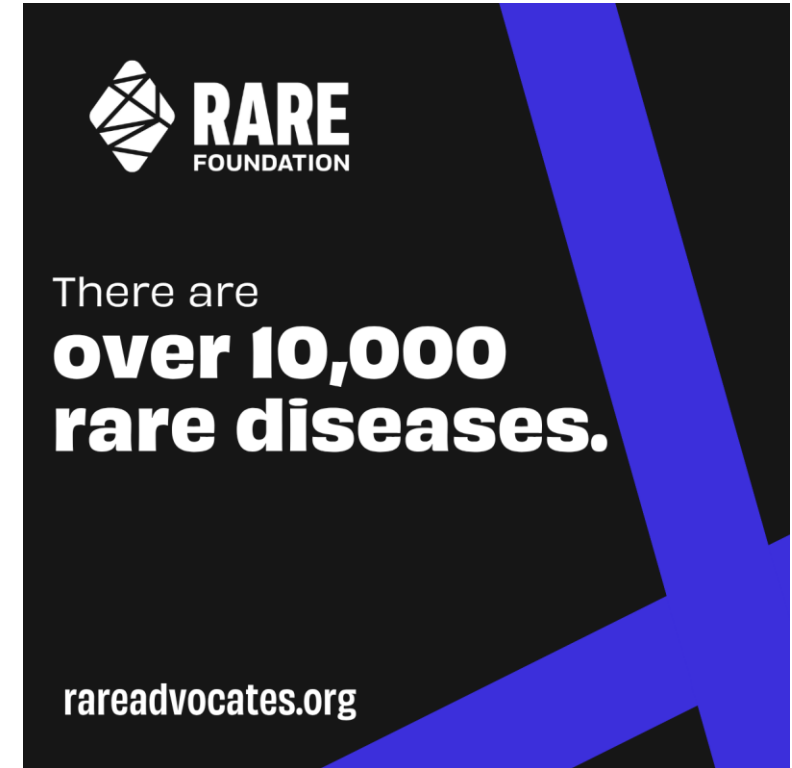
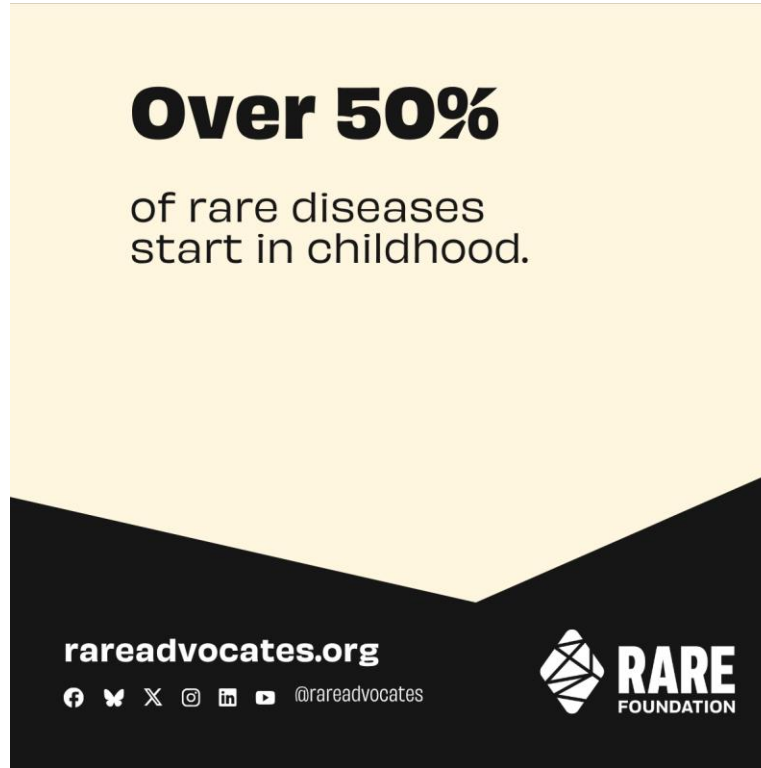
Story Template 4: Hope for the Future

- “Living with [name of rare disease / a rare disease] has been [challenging / exhausting / full of unknowns], but the RARE Foundation is working to make the future brighter. By [advocating for science-driven policy / pushing for faster research / ensuring access to care], they’re giving families like mine hope. I’m fundraising so that [future patients / children / families like ours] won’t have to face the same struggles.”

Story Template 5: Gratitude & Action

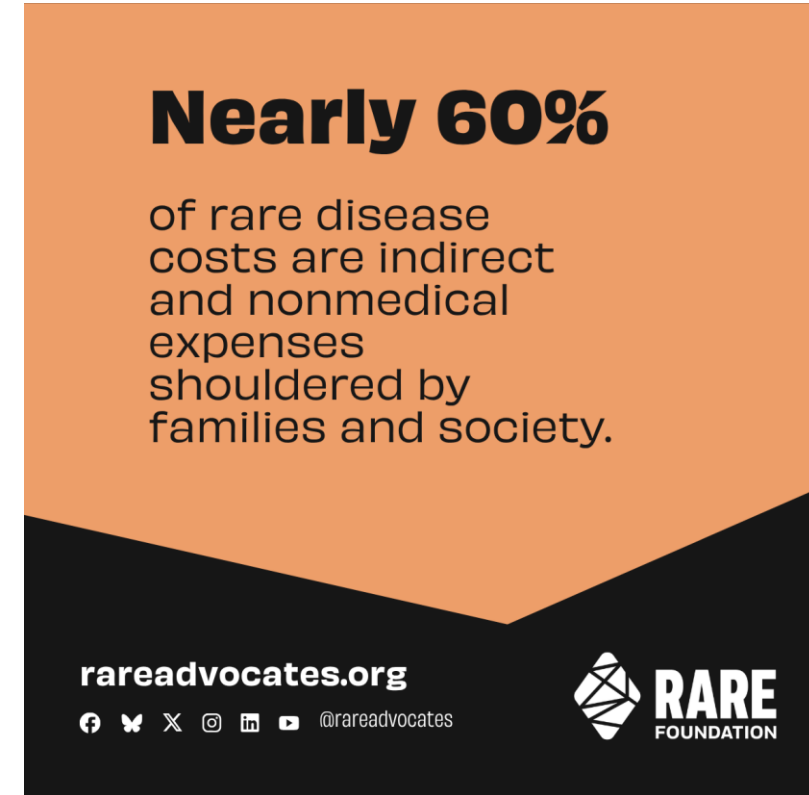
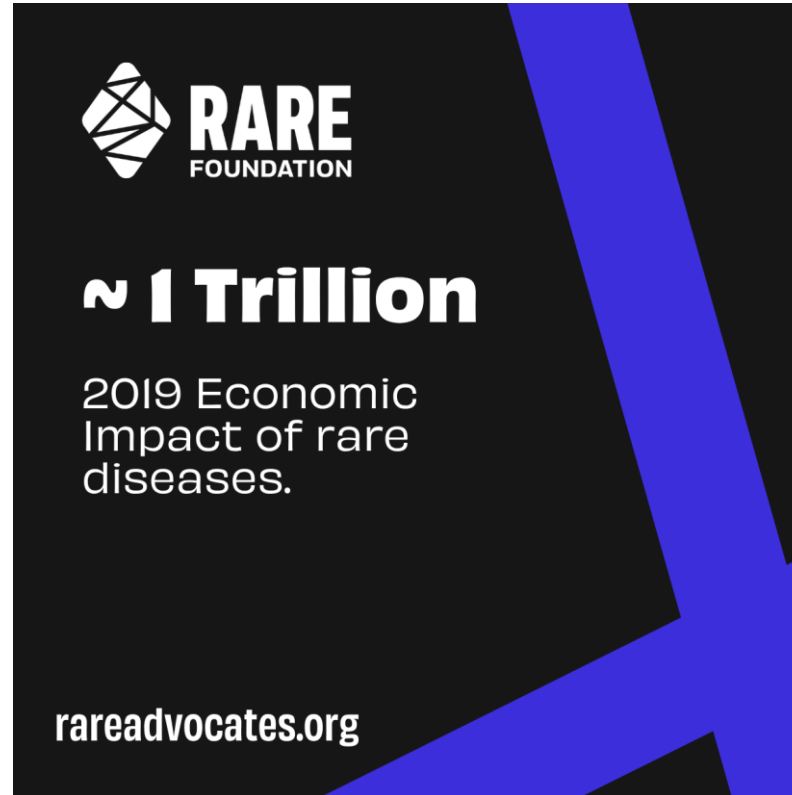
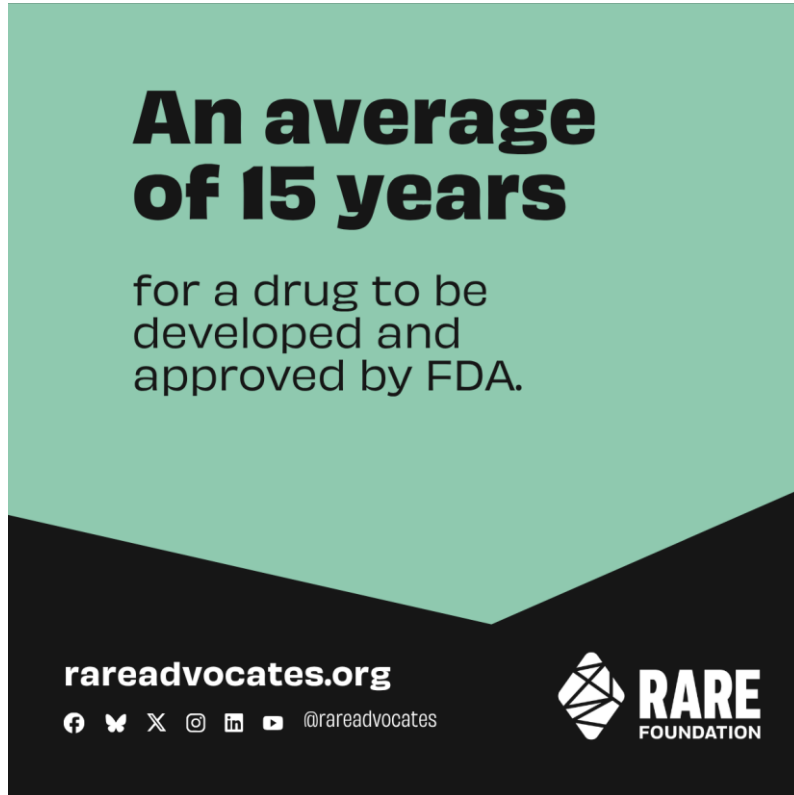
- “I’m grateful for the support I’ve received from [family / friends / the RARE Foundation community], but I know so many others still face [isolation / long waits for diagnosis / limited treatment options]. That’s why I’m taking action by fundraising for the RARE Foundation. With your support, we can [amplify rare disease voices / fuel advocacy / bring change faster] for those who need it most.”

Approved Social Media Graphics



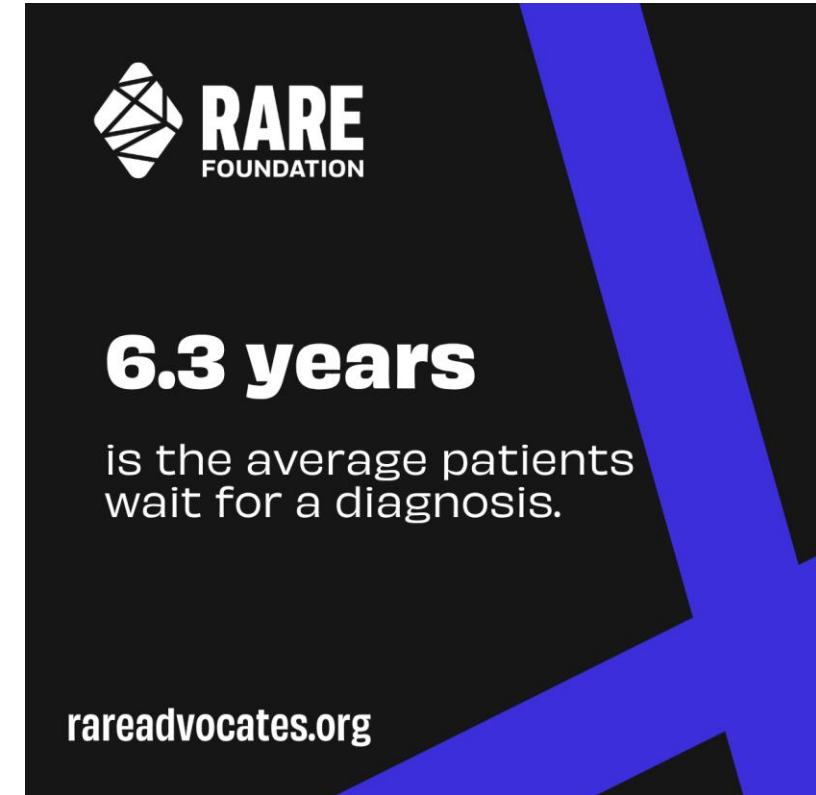
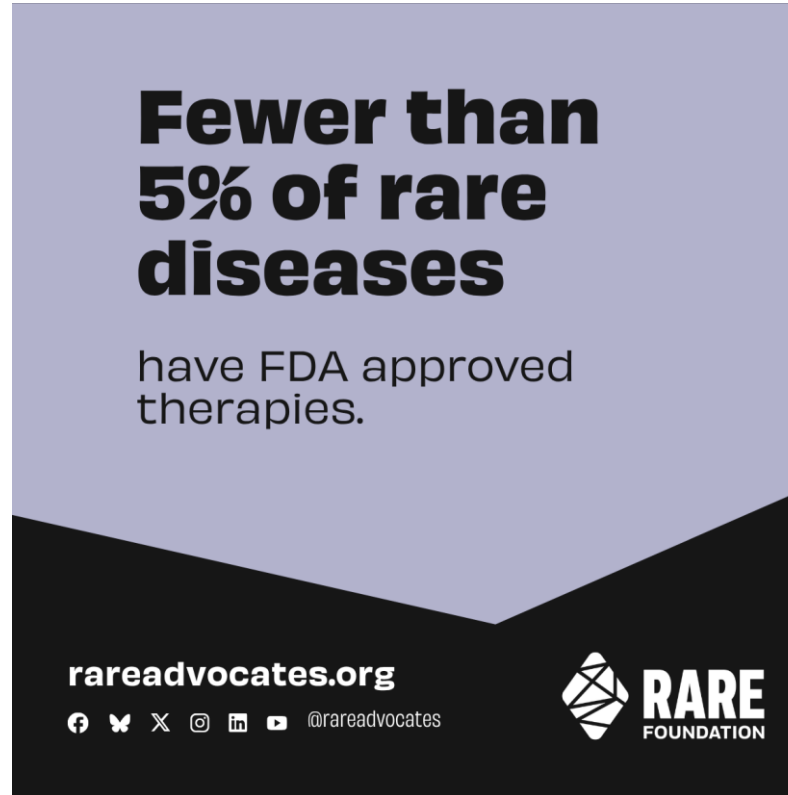
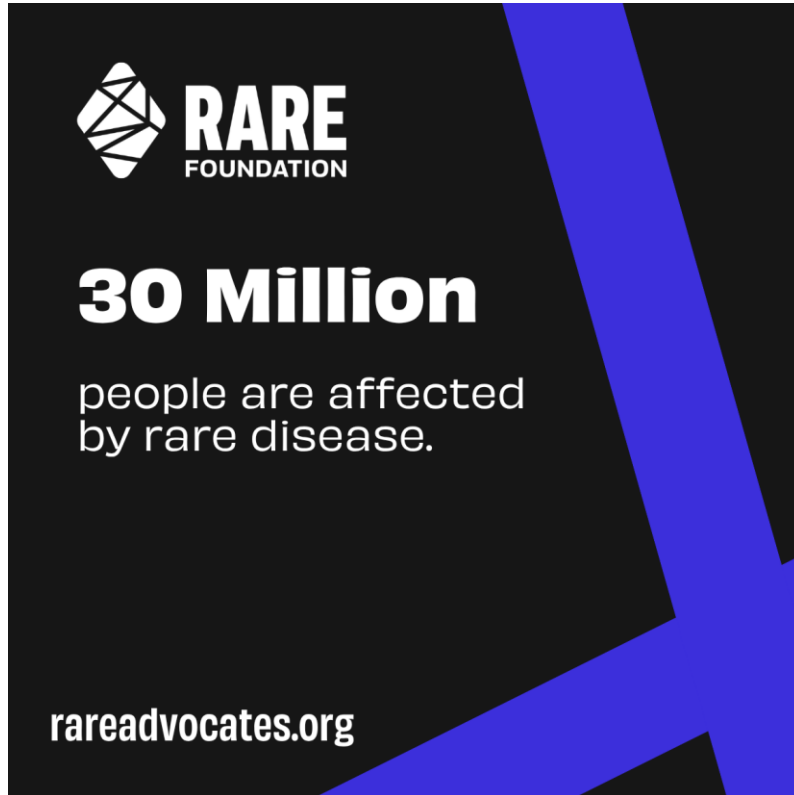
To use: right-click image and select Save as Picture, then upload the saved PNG to your social media.

Approved Social Media Graphics



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Approved Social Media Graphics



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Contacts

Have a question along the way? Please reach out! We're honored to help at any stage of your fundraiser.

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Thank you!