



Rare Diseases & Orphan Products Breakthrough Summit®

October 16-17, 2023 | Washington, DC



2023 NORD Breakthrough Summit® Social Media Toolkit

Welcome and thank you for registering for the 2023 NORD Rare Diseases and Orphan Products Breakthrough Summit!

As a rare disease community member or supporter, you are uniquely suited to help drive conversations and influence key stakeholders to join us for NORD's 2023 Breakthrough Summit in Washington, DC this October. Together, we will share insights, identify opportunities, and collectively solve the biggest challenges facing the rare disease community today and into the future.

We welcome and challenge you to help make the 2023 Breakthrough Summit the most successful one in its 13-year history! You can help by spreading the word, inviting colleagues, informing partners, sharing with decision makers and influencing the influencers.

The following is a social media toolkit that will help you to showcase your attendance at this year's #NORDSummit. It's our goal to help generate pre-event excitement and bring the best of the best to this important event. We request your support by sharing that you are attending the NORD 2023 Breakthrough Summit with your peers and networks – show on your social channels. **This toolkit includes a graphic for social media, sample post copy, and tips for participating online in advance of the event.**

Thank you for your support. We're excited to have you join us for this signature event!

Did You Know?!

- One in ten people in the US have a rare disease. That's more than 30 million of our loved ones, friends, colleagues, and neighbors.

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- From small towns to large cities, rare diseases are an urgent public health challenge, and no family is immune.
- Fewer than 5% of the more than 7,000 known rare diseases have an FDA-approved treatment.
- Patients with rare diseases incur nearly half of all health care costs in the US, with medical costs three to five times higher than non-rare patients.
- 40 years ago, the coalition of rare patients and caregivers who successfully advocated for the Orphan Drug Act formed the National Organization for Rare Disorders (NORD) to be a voice for the entire rare community in the United States.

Helpful Tips for Social Media:

- **Attach an image to your post** – Use one of the assets we have provided below or get creative! Some suggestions include: a shot that encapsulates your engagement or role at the event or a shot from a previous NORD event.
- **Use the hashtag #NORDSummit** – Be a part of the conversation this year by including the official NORD Breakthrough Summit hashtag in all your posts.
- **Engage with your followers** – If you receive questions or comments about your posts, we encourage you to respond to them and start conversations! If there is a question you can't answer, tag us in the comments and we'll respond.
- **Tag your followers** – Is there someone that you know would love to be at the NORD Breakthrough Summit? Tag them in your posts or send them an email or message to let them know you want to see them there.

NORD's Social Media Platforms:

We appreciate you tagging NORD in your posts using the handles below:

- **Facebook:** @NationalOrganizationforRareDisorders
- **Twitter:** @RareDiseases
- **LinkedIn:** @NationalOrganizationforRareDisorders
- **Instagram:** @nord_rare

Customizable Posts

Please use the suggested posts on the following pages on your social media channels and customize them to fit your voice and plans for the Summit

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[CLICK HERE TO DOWNLOAD THE 2023 PROMO GRAPHIC](#)

Use [this image](#) for you to promote your attendance at the NORD Breakthrough Summit. Download and use it across your social media, email, and website. The square version will work best on **Instagram**, while the horizontal is sized for **Facebook**, **Twitter**, and **LinkedIn**.

Twitter

- I'm thrilled to join @RareDiseases in Washington, DC on October 16-17 for the 2023 #NORDSummit! This year's agenda will feature a lineup of experts discussing the most pressing topics affecting the #RareDisease community! Register to join me there: nordsummit.org
- I look forward to joining hundreds of #RareDisease advocates and leaders during the 2023 #NORDSummit on October 16-17! Sessions and speakers will cover topics from #AcceleratedApproval to #NewbornScreening to #GeneTherapy and more. I hope to see you there! nordsummit.org
- I will be attending this year's #NORDSummit in DC on October 16-17! @RareDiseases has a dynamic agenda planned, focused on the most critical topics in the #RareDisease community and #OrphanProducts field, including conversations with #FDA. Check it out: nordsummit.org

Facebook/LinkedIn

- More than 30 million Americans, meaning 1 in 10 of us, live with a #RareDisease. I'll be joining hundreds of rare disease community advocates, as well as leaders in research, at the 2023 NORD Breakthrough Summit this October in Washington, DC. Don't miss the opportunity to join me there and help reimagine what is possible for rare disease treatments and cures. Register for the #NORDSummit now: nordsummit.org
- I am thrilled to share that I will be attending NORD's annual Rare Diseases + Orphan Products Breakthrough Summit in Washington, DC this October! This highly

anticipated conference brings together a huge intersection of #RareDisease stakeholders to discuss critical topics within the rare community. I hope to connect with you there! Register for the #NORDSummit here: nordsummit.org

Instagram

Please make sure to include the link to nordsummit.org in your Instagram bio.

- I am thrilled to share that I will be attending this year's @nord_rare Rare Diseases + Orphan Products Breakthrough Summit in Washington, DC on October 16-17. This event will bring together hundreds of advocates and leaders in rare disease research for productive discussions and collaborative solutions that will ground the work we do for years to come. I hope to see and connect with you there! Register for the #NORDSummit today at the link in my bio (nordsummit.org)
- An estimated 30 million Americans, 1 in 10 of us, live with a #RareDisease. I'll be joining hundreds of advocates from this far-reaching community, as well as leaders in research, at the 2023 @nord_rare Breakthrough Summit this October in Washington, DC. I encourage you to join me there and help reimagine what is possible for rare patients and families. Register for the #NORDSummit at the link in my bio! (nordsummit.org)