

LIVING RARE,
LIVING STRONGER®
NORD® PATIENT AND FAMILY FORUM

Featuring the Rare Impact Awards®

JUNE 26, 2022
CLEVELAND, OHIO

LONG LIVE ROCK

2022 LIVING RARE, LIVING STRONGER® NORD® PATIENT AND FAMILY FORUM FEATURING THE RARE IMPACT AWARDS®

SOCIAL MEDIA TOOLKIT

As a trusted voice in the rare disease community, you are the perfect fit to help drive the conversation leading up to this valuable community event. The event is only as meaningful as the passionate advocates who attend it – so we appreciate your help in spreading the word.

Please use this social media toolkit as a guide to share content and generate excitement before the event, encouraging your colleagues and networks to attend and/or follow the conversation online.

The toolkit includes helpful tips for using social media, customizable template posts, links to official social media properties including profile handles, hashtags and digital assets. Upon receipt of the toolkit, we ask you to review the material and personalize the content so that it is most authentic to you and your followers. Thank you for contributing to the success of the forum. Happy sharing!

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Helpful Tips for Social Media

- **Attach an image to your post** – feel free to use NORD’s images [here](#) (a zipped folder will download to your computer) or get creative! Some suggestions include: your favorite on-stage shot from a previous speaking engagement, a shot that captures a memory that encapsulates your speaking points, or a shot from a previous NORD event.
- **Engage with your followers** – if you receive questions or comments about your posts, respond to them. Social media is all about the engagement between followers and having a conversation. If there is a question that you can’t answer, feel free to tag us in the comments and we’ll be happy to jump in.
- **Tag your followers** – is there someone who you know would love to participate at the Living Rare Forum with you? Tag them in your posts to let them know that you want to see them there.
- **Character Limits:**
 - 280 characters – is the character limit on Twitter
 - 2,200 characters – is the character limit on Instagram
 - 63,206 characters – is the character limit for Facebook
 - Shorter posts tend to be more effective
 - 3,000 characters – is the character limit for LinkedIn
 - Shorter posts tend to be more effective

Social Media Properties

The official event hashtags are **#LivingRareForum** and **#RareImpact**. Please use these hashtags in all of your posts before and during the event in an effort to create one centralized conversation about the important topics we will be discussing.

Feel free to tag NORD in your posts using the profiles below:

Facebook: @NationalOrganizationforRareDisorders

Twitter: @RareDiseases

LinkedIn: @NationalOrganizationforRareDisorders

Instagram: @nord_rare

Images located [here](#) (a zipped folder will download onto your computer) were created to promote the event, please feel free to download these images and share them across your social media accounts.

Customizable Post Templates

Below you will find customizable post templates that you can fill in for easy sharing. Feel free to get creative and share content that you feel would resonate best with your networks.

Twitter

- This year's #LivingRareForum featuring the #RareImpact Awards will take place in Cleveland, Ohio on June 26! @RareDiseases is excited to be back in person for the opportunity to connect & learn with those in the #rare community. See you there! More: livingrare.org {upload image provided or your own}
- We are excited to join @RareDiseases & the #RareDisease community back in person for the #LivingRareForum & #RareImpact Awards! The agenda will feature a lineup of experts & sessions to educate patients, caregivers & advocates in Cleveland, Ohio! Register: livingrare.org {upload image provided or your own}
- Register now for NORD's #LivingRareForum on June 26! There are limited spaces with this event being in person in Cleveland, Ohio, so don't miss out on the chance to learn, network and discuss with the #RareDisease community! Visit livingrare.org to register.
- @RareDisease's #RareImpact Awards are taking place following the #LivingRareForum in Cleveland, Ohio on June 26! This event will honor the rockstars of the #RareDisease community. Visit livingrare.org to register and see this year's nominees. {upload image provided or your own}

Facebook/LinkedIn/Instagram

- We are proud to support the {tag NORD on channel of your choice, see page 2} Living Rare, Living Stronger Patient & Family Forum and Rare Impact Awards. During the event, patients, caregivers and advocates in the rare disease community will attend empowering panels and connect with other members of the #RareDisease community. Visit NORD's website at livingrare.org to learn more and register to join us in Cleveland on June 26. #LivingRareForum #RareImpact {upload image provided or your own}
- I am excited to join {tag NORD on channel of your choice, see page 2} in Cleveland, Ohio for the Living Rare, Living Stronger Patient & Family Forum and Rare Impact Awards happening on June 26! Please join me by registering for the event at livingrare.org #LivingRareForum #RareImpact {upload image provided or your own}
- {tag NORD on channel of your choice, see page 2}'s Living Rare, Living Stronger Patient & Family Forum and Rare Impact Awards will be held on June 26 in Cleveland, Ohio. The #LivingRareForum is a great opportunity to learn, network and discuss the rare community with patients and families, organization leaders, and health care professionals. Visit NORD's website at livingrare.org to learn more. {upload image provided or your own}
- We are excited to attend {tag NORD on channel of your choice, see page 2}'s Rare Impact Awards on June 26 in Cleveland, Ohio. Join us in celebrating #RareDisease rockstars and honoring those individuals, groups and companies making strides on behalf of the millions impacted by rare disease. Visit livingrare.org to register and see this year's nominees. {upload image provided or your own}