



NORD's 40th Anniversary Celebration & the Rare Impact Awards[®]

& **Living Rare, Living Stronger[®]**
Patient & Family Forum

MAY 4 + 6, 2023 | WASHINGTON, DC



2023 LIVING RARE FORUM + NORD'S 40TH ANNIVERSARY CELEBRATION & 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!

1779 MASSACHUSETTS AVENUE NW, SUITE 500
WASHINGTON, DC 20036
T 202-588-5700 ■ F 202-588-5701

55 KENOSIA AVENUE
DANBURY, CT 06810
T 203-744-0100 ■ F 203-263-9938

1900 CROWN COLONY DRIVE, SUITE 310
QUINCY, MA 02169
T 617-249-7300 ■ F 617-249-7301

rarediseases.org ■ orphan@rarediseases.org

NORD[®], icon, Living Rare Living Stronger and Rare Impact Awards are registered trademarks of the National Organization for Rare Disorders.

NORD is a registered 501(c)(3) charity organization. NRD-2269

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.
- **Engage with NORD!** NORD, along with our member organizations, will be posting frequently on our social media channels leading up to the event. We would love to see you commenting under posts, sharing with friends and family, or tagging your favorite celebrity or elected official under our posts. Your efforts do not go unnoticed, and we rely on you to help bring awareness to the rare disease community.

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.

Here are some of NORD’s social media profiles and hashtags:

Facebook: @NationalOrganizationforRareDisorders

Twitter: @RareDiseases

LinkedIn: @NationalOrganizationforRareDisorders

Instagram: @nord_rare

A character limit is the maximum amount you can write in your post. Spaces, letters of the alphabet, numbers, and punctuation all count toward a character limit. Here is a quick character limit guide, though posts that are shorter tend to perform better:

- Twitter: 280 characters
- Instagram: 2,200 characters
- LinkedIn: 3,000 characters
- Facebook: 5,000 characters

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

- The 2023 #LivingRareForum and the #RareImpact Awards will take place in Washington, DC on May 4 + 6! @RareDiseases is excited to bring people together to connect & learn with those in the #rare community. See you there! livingrare.org {upload image provided or your own}
- CAN'T MISS WEEKEND INCOMING: May 4 is the #RareImpact Awards and May 6 is the #LivingRareForum – both in Washington, DC. Members of the #raredisease community – visit livingrare.org to secure your place!
- We are excited to join @RareDiseases & the #RareDisease community for the #LivingRareForum & #RareImpact Awards! The agenda will feature a lineup of experts & sessions to educate patients, caregivers & advocates in Washington, DC! Register: livingrare.org {upload image provided or your own}
- In celebration of @RareDisease's 40th Anniversary the 2023 #RareImpact Awards are taking place on May 4 in Washington, DC! This event will honor the rockstars of the #RareDisease community. Visit rareimpact.org to register. {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 Washington, DC this May. #LivingRareForum #RareImpact {upload image provided or your own}
- I am excited to join {tag NORD on channel of your choice, see page 2} in Washington, DC for the Living Rare, Living Stronger Patient & Family Forum and Rare Impact Awards happening in May! Please join me by registering for these events 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 May 4 & 6 in Washington, DC. 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 May 4 in Washington, DC. Join us in celebrating NORD's 40th Anniversary as we honor those individuals, groups and companies making strides on behalf of the millions impacted by rare disease. Visit rareimpact.org to register and see this year's nominees. {upload image provided or your own}