



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

MEDIA GUIDELINES

STATEMENT OF PURPOSE

These guidelines are intended to provide helpful information to journalists who are interested in participating in and publishing information about the 2021 Living Rare, Living Stronger® NORD® Patient and Family Forum.

PRIVACY OVERVIEW

To protect the well-being and comfort of speakers and attendees, some sessions of Living Rare, Living Stronger may be closed to the media. This information will be announced prior to the event/session.

SOCIAL MEDIA

The event hashtag for Living Rare, Living Stronger is #LivingRareForum. Attendees are encouraged to use the event hashtag when sharing content on social media.

ELIGIBILITY REQUIREMENTS

Complimentary registration is reserved for individuals who will produce news coverage of the event and meet the following requirements:

- Individual is a credentialed journalist from a recognized, external print, broadcast, syndicated or online news organization
- Individual is a writer or editor from an online patient community
- Individual is a writer or editor from an online medical professional community

A maximum of two representatives from any news outlet will be allowed to register. If additional press registrations are needed, please contact NORD's Communications Department at media@rarediseases.org.

HOW TO REGISTER

To register as a member of the press, please contact media@rarediseases.org. Identification certifying that you are a member of the news media is required, including any of the following:

- Government-issued or media outlet press ID; business card showing verifiable current employment; or current membership card from the National Association of Science Writers
- News outlet webpage listing you as news staff (news director, editor, producer, reporter or anchor)
- Letter from the editor/producer on company letterhead or from a company email address that states you are covering the event on assignment

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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

SCIENTIFIC/MEDICAL JOURNALS

Only those scientific/medical journals that have regular sections for editorial news coverage may apply for complimentary registration.

IDENTIFICATION

Members of the news media are required to identify themselves as being with a media outlet whenever participating in the Forum (i.e. when posting or answering a question, when connecting with an attendee, etc.).

RESTRICTED ACCESS

As stated above, to protect the well-being and comfort of speakers and attendees, some sessions of the Living Rare, Living Stronger NORD Patient and Family Forum will be closed to members of the media. This information will be made available prior to the event/session.

INTERVIEWS

NORD's Communications Department can facilitate scheduling interviews with NORD staff and Rare Impact Award honorees. If you are interested in scheduling interviews with other speakers and attendees, you must gain consent from those individuals and make arrangements with them directly.

RECORDING AND PHOTOGRAPHY

Filming, screenshots and photography are prohibited for publication unless there is an agreement with NORD executed in advance of the event. Journalists who wish to record audio or video may do so for note-taking purposes only, and may not post or broadcast audio or video excerpts.

CODE OF CONDUCT AND HARASSMENT POLICY

Media in attendance must follow NORD's event Code of Conduct, which is applicable to all guests and is available on NORD's website. NORD wishes for the event to be a positive experience for all and to that end will not tolerate harassment of any kind.

VIOLATIONS

Any member of the press who violates these policies may have his or her press pass revoked. NORD reserves the right to revoke press access and credentials for current and future NORD events without obligation on the part of NORD for refund of any fees.

PRESS LIST POLICY

NORD does not share its press list or the names of press who are registered to attend.

CHANGES TO MEDIA GUIDELINES

These policies are subject to change at any time. For questions or further information, please contact: media@rarediseases.org.

QUESTIONS

For any questions, please contact media@rarediseases.org. Thank you!

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