



## **Media Guidelines for the 2019 Living Rare, Living Stronger NORD® Patient and Family Forum featuring the 2019 Rare Impact Awards**

### **STATEMENT OF PURPOSE**

These guidelines are intended to provide helpful information to journalists who are interested in attending and publishing information about the 2019 Living Rare, Living Stronger NORD® Patient and Family Forum and/or the 2019 Rare Impact Awards.

### **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 is #LivingRareForum.

### **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](mailto:media@rarediseases.org).

## HOW TO REGISTER

To register as a member of the press, please contact [media@rarediseases.org](mailto:media@rarediseases.org). Advanced registration is preferred whenever possible and on-site registration is not guaranteed. 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

## SCIENTIFIC/MEDICAL JOURNALS

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

## PRODUCTION COMPANIES AND FILM CREWS

Production companies and documentary film crews that wish to attend must submit a written request to [media@rarediseases.org](mailto:media@rarediseases.org) at least two weeks in advance of the event.

## ON-SITE GUIDELINES

### NAME BADGES

Members of the news media are required to wear name badges at all times while in attendance. The name badge with an attached “press” flag or other similar notice will be provided upon check-in at registration. Badges should be visible at all times. NORD press badges are non-transferable. Lost badges should be reported to the registration desk immediately.

### 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. If you are interested in scheduling interviews with other speakers and attendees, you must gain consent from those individuals directly.

### RECORDING AND PHOTOGRAPHY

Filming and photography are prohibited unless there is an agreement with NORD executed in advance of the event. Media must obtain permission of each speaker, moderator, audience member and attendee before the individual’s likeness is published. Journalists who wish to record audio may do so for note-taking purposes only, and may not post or broadcast audio excerpts. Any photo, video or audio recording that is considered disruptive will be asked to cease immediately.

## 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 attendees 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 and may be asked to leave the premises at the discretion of NORD staff. 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](mailto:media@rarediseases.org).

## QUESTIONS

For any questions, please contact [media@rarediseases.org](mailto:media@rarediseases.org). Thank you!

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