



## GUIDELINES FOR NEWS MEDIA COVERING THE NORD 2018 RARE DISEASES & ORPHAN PRODUCTS BREAKTHROUGH SUMMIT

INCLUDING PUBLIC RELATIONS OFFICE GUIDELINES FOR EXHIBITORS, SPONSORS AND OTHER INDUSTRY REPRESENTATIVES

October 15-16, 2018, Washington, D.C.

## NEWS MEDIA REGISTRATION AND CREDENTIALS

### ELIGIBILITY REQUIREMENTS

Complimentary registration and on-site access for news media is available to credentialed journalists from recognized external print, broadcast, syndicated or online news organizations. Complimentary registration is solely for those individuals who will produce news coverage of the conference. News media outlets must be in existence and regularly (daily/weekly) covering health and science-related topics, including rare diseases and/or public health policy, for at least six months to be eligible to send journalists to the NORD Summit.

News media must register to attend and be registered in advance by NORD.

Members of the news media are required to wear name badges at all times while attending the Summit. The name badge will be provided upon check-in at registration. If a reporter violates this guideline, NORD reserves the right to revoke press access and credentials for the current and future NORD conferences and events.

After registering, members of the news media will be eligible to receive advance access to embargoed news materials.

A maximum of four representatives from any news media outlet will be allowed to register. If additional press registrations are needed, please contact the Communications Department at <https://rarediseases.org/inquiries/>.

Those who do not qualify for complimentary NORD Summit news media registration or event press badges include, but are not limited to, the following:

- **Publishers or a publication's advertising, marketing, public relations or sales representatives.**
- Publishers, editors or writers from internal publications or newsletters.
- Book publishers and book authors.
- Public relations, marketing, advertising or sales staff of NORD exhibitors, sponsors or educational institutions, or other companies, or their PR firms or consultants.
- Financial, market and industry analysts; employees of financial, market and industry analyst firms and medical communications companies. Employees of companies whose primary business is as investment advisors or business consultants. Employees of business information/intelligence services, publications and databases.
- Other individuals who are not actually reporting on the meeting.
- Freelancers working without an assignment.



- Non-news media websites, such as blogs not associated with accredited news media or which carry primarily personal information and opinion. Sponsored blogs or blogs of for-profit companies that do not have independent editorial staff.
- Individuals whose purpose is to repackage content for continuing medical education (CME) opportunities, research studies and textbooks.
- Scientists presenting data at NORD may not register as journalists; they must register in the conventional manner. Individuals registered as journalists are not eligible for CME credits. All of these individuals are welcome to register for NORD as regular attendees.

## CREDENTIALS

To register as a member of the press and to obtain a press badge, identification certifying that you are a member of the news media is required. This includes the following:

- Government-issued or media outlet press ID; or a business card showing verifiable current employment as a reporter/writer/editor at a recognized news media outlet; or a current membership card from the National Association of Science Writers.
- A news outlet webpage listing you as news staff (news director, editor, producer, reporter, anchor).
- Letter from the editor/producer on station/network letterhead or from a company email address that states you are covering the NORD Summit on assignment.
- **Copies of news coverage of the previous year's Summit, if you were registered as a journalist for that event.**

## FREELANCERS

In addition to the materials listed above, freelancers must also submit:

- **A letter on the media outlet's letterhead stating that you are on assignment to cover the NORD Summit.**
- At least two copies of bylined articles published in the last year for recognized news media outlets covering health- or medical-related topics, particularly research/science, health policy, and rare diseases.

## SCIENTIFIC/MEDICAL JOURNALS

Only those scientific/medical journals that have regular sections for editorial news coverage may apply for complimentary registration as a journalist at NORD. Only those people who generate that editorial content may apply.

## PRODUCTION COMPANIES AND FILM CREWS

Production companies and documentary film crews that wish to register for the NORD Summit as journalists must submit a written request at least two weeks in advance of the conference. Requests must include:

- Information on the production company.
- A film/documentary treatment.



- Marketing and distribution plans.
- Information on sponsors.
- List of planned and/or requested interviews.

## NEWSLETTERS

Newsletters that are widely published and publicly available, published regularly (at least six times/year), and that primarily cover rare disease news are eligible to credential one journalist. Investment, corporate, internal and institutional newsletters are not eligible for news media credentials. Applicants must submit two recent issues of the newsletter, each containing at least one **bylined medical/health/science article, and coverage from the previous year's Summit (if applicable).**

## ON-SITE REGISTRATION

On-site registration for members of the press is not guaranteed. Credential requirements are the same for on-site registrants as advance registrants (see above).

## NEWS EMBARGO POLICY

**Embargoed NORD news materials are intended specifically for each journalist's individual use and are not to be shared in any way with anyone until the news embargo date/time has passed.**

By accepting embargoed NORD news materials, journalists acknowledge that the materials are solely for their use and that they will not distribute, publish, broadcast or in any other way share them before the news embargo time has passed. If a reporter or news media outlet breaks an NORD news embargo, NORD reserves the right to revoke their press access and credentials for the current event and future NORD conferences and events.

All news media representatives, scientists, funders of science presented at NORD, and NORD exhibitors/sponsors agree to be bound by news embargoes and release times stated on news releases and other news materials issued by NORD.

## GENERAL SESSIONS

All materials presented at the NORD Summit are embargoed for publication and broadcast until the date and time of presentation at the conference, or an embargo date and time specified in advance, such as on a press release. If there are questions, please contact NORD Public Relations Department at <https://rarediseases.org/inquiries/>.

## POSTER SESSION

The news embargo on abstracts and scientific presentations included in the 2018 NORD Summit Poster Session is at the scheduled beginning of the conference, Monday, October 15, 2018 at 7:00 A.M. ET, unless otherwise stated in a press release that includes that abstract/presentation.

## BREAKOUT SESSIONS

News embargoes for breakout sessions are at the beginning of each individual talk.



## NEWS BRIEFINGS

NORD may host possible news briefings during the Summit. If a news briefing is planned, a schedule that lists topics, times and presenters will be posted in the Media Room and on the NORD Summit website, as applicable.

## VIDEO/PHOTO/AUDIO REGULATIONS

### FILMING AND PHOTOGRAPHY

Filming and photography at the NORD Summit and in the NORD Summit poster/exhibit hall area are prohibited unless there is a signed contract with NORD executed in advance of the meeting. Television, video crews and still photographers covering the meeting are required to check-in upon arrival at the registration desk each day.

As a courtesy to presenters, television and video crews and photographers must obtain permission of the speaker and moderator before filming presentations. Television and video crews may not use artificial lights during presentations. Flash photography is prohibited.

### AUDIO RECORDING

Journalists who wish to record audio of speeches and scientific presentations may do so for note-taking purposes only, and may not post or broadcast audio excerpts. If you plan to record audio for note-taking, you must alert NORD Communications staff as you initially register and sign the form provided at the registration desk.

Any photo, video or audio recording that is considered disruptive by NORD Communications staff or other conference staff and speakers/scientific presenters will be asked to cease immediately. If a **disruptive activity is not stopped, the journalist's registration is subject to withdrawal** and the person is subject to removal from the conference.

### SCIENTIFIC PAPERS & VISUALS

Journalists who want to view and reproduce posters, slides, graphs and other visuals to illustrate news coverage **must have the presenters' permission**. NORD Communications staff will assist with requests to use such materials.

### SCIENTIFIC POSTERS & EXHIBITS

Crews and photographers are asked not to interrupt researchers and others who are studying scientific posters and exhibits. Researchers can be interviewed in lounge areas or as they leave the scientific poster and exhibit areas.

Press releases related to poster presentations will be accessible through the NORD Summit website.

## ON-SITE USE OF MEDIA ROOM

A quiet area designated as a Media Room will be available for registered journalists to conduct interviews and/or file stories. The Media Room may be reserved in advance by contacting NORD



Communications department or by speaking a member of the NORD Communications department on site. NORD Communications staff will coordinate the use of these quiet spaces.

## SECURITY AND CODE OF CONDUCT INFORMATION

### NAME BADGES

**NORD name badges with an attached “press” flag are required for admittance to all NORD-related presentations and events.** Badges should be worn and visible at all times. Lost badges should be reported to the registration desk and be handed over to NORD Communications staff immediately. The following badge policies will be in effect throughout NORD:

- NORD press badges are the sole property of NORD.
- NORD press badges are non-transferable.
- False certification of individuals as paid NORD attendees, misuse of press badges, any method of assisting unauthorized persons to gain access to any NORD presentation or event, or any inappropriate or unauthorized conduct will be just cause for repossessing badges of all individuals involved, and expelling all parties involved from the NORD Summit without obligation on the part of NORD for refund of any fees. NORD reserves the right to revoke the press access and credentials for the current event and future NORD conferences and events for any registered journalist who fails to adhere to these policies or who misuses his/her news media privileges to engage in activities other than journalistic pursuits.

### CODE OF CONDUCT AND HARASSMENT POLICY

**Members of the press in attendance must follow NORD’s event Code of Conduct, which is applicable to all guests and is available on the NORD website.** Members of the press who violate this policy may have their press pass revoked and may be asked to leave the premises at the discretion of NORD.

NORD wishes for the Summit to be a productive and positive experience for all attendees and to that end will not tolerate harassment of any kind. Any member of the press who repeatedly questions a **NORD Summit attendee, speaker or presenter, despite the individual’s requests for privacy or decline to comment,** may have their press pass revoked and may be asked to leave the premises at the discretion of NORD.

## GUIDELINES FOR EXHIBITORS, SPONSORS AND OTHER ATTENDEES

### PRESS LIST POLICY

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

### MEDIA ROOM AND NEWS BRIEFINGS

The NORD Media Room is open only to members of the working press. Exhibitor and sponsor staff and representatives are not allowed in the Media Room. As a courtesy to news media representatives, NORD discourages these individuals from standing outside the Media Room in an effort to meet with journalists. Quiet areas may be available for sponsor/exhibitor representatives accompanied by



registered journalists to conduct interviews. NORD Communications staff may be available to help schedule use of these spaces.

### SPONSOR AND EXHIBITOR NEWS RELEASES

As a convenience for journalists, news releases from exhibitors and sponsors related to science being presented at NORD will be displayed in a designated area of the Media Room. Only news materials related to science being presented at NORD will be accepted – no promotional material or background material, and no press kits. NORD does not endorse news materials from exhibitors and sponsors. NORD must approve all exhibitor/sponsor media materials before they are displayed at the NORD Summit. NORD reserves the right not to approve the materials for any reason. News releases **must state that the data “was presented at the NORD 2018 Rare Diseases & Orphan Products Breakthrough Summit.”** First references to the conference in all news materials must use that full name. The “NORD Rare Summit” or “NORD Summit” are acceptable on subsequent references. In addition, all references in news materials to the “National Organization for Rare Disorders (NORD)” must use this full name in the first reference. “NORD” is acceptable on subsequent references.

Approval Process: Prior to Wednesday, October 10, 2018, a review copy of all exhibitor/sponsor media materials must be sent to NORD Public Relations staff at [marketing@rarediseases.org](mailto:marketing@rarediseases.org). Materials not received by October 9, 2018 will not be displayed at the NORD Summit. Up to 100 copies of accepted press materials can be dropped off to a staff person at the Media Room during regular hours of operation. Communications staff will not make copies of outside press materials.

### NEWS BRIEFINGS

At the discretion of NORD Communications staff, up to two representatives from an exhibitor/sponsor may attend any potential NORD news briefing at which science they have funded or conducted is presented.

NORD prohibits all news events, including news conferences, news briefings, webcasts and media receptions, on-site at the NORD Summit, during normal hours of the NORD Summit (generally 8:00 a.m.–6:00 p.m., specific times TBD).

### CHANGES IN NEWS MEDIA GUIDELINES

These policies are subject to change at any time. For questions or further information, please contact: [marketing@rarediseases.org](mailto:marketing@rarediseases.org).



**a new era of patient-focused innovation**

**RARE DISEASES & ORPHAN PRODUCTS BREAKTHROUGH SUMMIT**



October 15-16, 2018 | Washington, D.C.  
[nordsummit.org](http://nordsummit.org)



Updated July 2018