**NORD MISSION STATEMENT**

*NORD is committed to the identification, treatment and cure of rare diseases.*

*Improving the lives of people impacted by rare diseases.*

*Fighting for the rare disease community for over 35 years.*

The National Organization for Rare Disorders (NORD®), an independent nonprofit, is leading the fight to improve the lives of rare disease patients and families.

We do this by supporting the rare community - its people and organizations. We work together to accelerate research, raise awareness, provide valuable information and drive public policy that benefits the estimated 25-30 million Americans impacted by rare diseases.

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**NORD’s personality is ALWAYS:**
- Upbeat & Positive
- Genuine & Warm
- Involved
- Empathetic
- Approachable

**NORD’s personality is NEVER:**
- Depressing or Negative
- Manipulative
- Indifferent
- Self-Absorbed
- Repellent
INSIDE NORD

NORD is here to support every member of the rare disease community with programs and services focused on one ultimate goal: To improve the lives of individuals and families affected by rare diseases.

EDUCATION
NORD and its members are leading a multi-front campaign to promote earlier diagnosis, optimal care and awareness of rare diseases.

We run educational programs for patients and caregivers, medical professionals, students and other stakeholders.

PATIENT ASSISTANCE
NORD provides assistance to patients and families struggling to obtain life-saving or life-sustaining treatment and care. These programs provide medication, financial assistance with insurance premiums and co-pays, diagnostic testing, caregiver respite grants and travel assistance to treatment sites and clinical trials.

MEMBERSHIP
NORD provides mentorship, education and support to more than 300 disease-specific patient organizations and over 10,000 individual advocates.

NORD is also home to the Rare Cancer Coalition, a unique group of advocates working collaboratively to fight rare cancers.

RESEARCH
NORD is accelerating research into treatments and cures through natural history studies, our registry program, as well as research we fund and conduct. We have been awarding research grants for 30 years.

POLICY AND ADVOCACY
NORD leads advocacy for rare diseases at the state and federal levels through through support from our Rare Action Network®.

We represent the voice of patients to advance basic and translational research, strengthen the drug development process and ensure access to affordable treatment.
**NORD COLORS**

Only these colors may be used. These colors can also be utilized as tints.

**Please Note:** Colors will vary slightly depending on whether they are printed on coated/uncoated paper or plastic.

## Primary Colors

<table>
<thead>
<tr>
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<td>R 0 / G 146 / B 188</td>
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<td>WEB: #0099BC</td>
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## Secondary Colors

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<td>PMS 7462c</td>
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NORD FONTS

There are two primary typeface families used in the NORD brand. Each of these typefaces convey a solid professional feel that clearly reflects NORDs personality.

**HEdline - Trade Gothic No. 20**

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

a b c d e f g h i j k l m n o p q r s t u v w x y z

1 2 3 4 5 6 7 8 9 0 ! @ #$ % ^ & * () - + =

**Body Copy - Myriad Pro Regular**

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

a b c d e f g h i j k l m n o p q r s t u v w x y z

1 2 3 4 5 6 7 8 9 0 ! @ #$ % ^ & * () - + =

The display sans serif font, TRADE GOTHIC No. 20, is primarily used for titles, headlines and subheads in either the Light, Book or Bold styles.

MYRIAD PRO REGULAR, is primarily used for body copy in a Regular format.

NORD fonts are located on the server (N:) Drive > _TEAMWORK > _NORD Brand Templates > _NORD Fonts

Default universal font for body copy should be CALIBRI if the NORD fonts are not available.
NORD LOGO

This logo represents several themes that are important to NORD and its members:
- Unity and connection
- Depth of commitment
- Cohesiveness
- Vibrancy and involvement
- Every part contributes
- 1 in 10 is affected

With the dawning of a new era for both rare diseases as well as orphan drug products, this logo signifies NORD’s awareness that, while our fundamental values remain unchanged, the issues have grown more complex. To encourage innovation in new therapy research and development, and to ensure patient access to new treatments, we must look to the future and embrace the promise of new ideas and new technologies.

Any mention of NORD (or NORD logo) in a publication, website or promotional item will need to have a registration mark ®. Please state at the bottom or back of piece:

“NORD and the NORD logo are registered trademarks of the National Organization for Rare Disorders. NORD is a registered 501(c)(3) charity.”
This policy provides our requirements regarding use of the National Organization for Rare Disorders (“NORD”) word marks and logotypes (this includes but is not limited to the “NORD” logo, its variants, and all NORD sub-brands, event logos and variants). NORD, and its sub-branded word marks, logos, slogans, copyrighted designs or other brand features of NORD are available for use or download on the NORD website.

As the need to address future branding concerns arises, we may cancel, modify, or change the terms of this policy without notice to the logo user (“You”). You are responsible for complying with any modified terms, so please review this policy and become familiar with any modifications we publish.

The NORD word marks, sub brands and logos are the sole and exclusive property of NORD. Your use of any word mark and/or logo implies acceptance of, and agreement with, the terms of this policy. If you do not accept and agree to follow the rules as set out in this policy, you do not have the right to use the word marks and/or logos and are prohibited from using them. Any use of NORD word marks and/or logos not in compliance with this policy is not authorized. If you violate the rules in this policy, you must cease and desist from all use of any NORD word marks and/or logos, regardless of the uses otherwise allowed in this policy. In addition, NORD reserves the right to revoke its approval of your use of the word marks and/or logos at any time.

Permission is granted to you to use the NORD word marks and logos only under the following terms and conditions:

Rules for Using the NORD Word Marks and/or Logos:
You must comply with all of the following rules when using a word mark and/or a logo:

- NORD’s logos and word marks are for non-commercial use only. Usage of NORD’s logos and word marks for commercial sales, individual fundraising or organizational fundraising is strictly prohibited unless otherwise expressed in writing by an authorized agent of NORD.
- Word marks and logos may not be used in an ambiguous way as described herein:
  - No word mark and/or logo may be used in any way that suggests that NORD is affiliated with, sponsors, approves or endorses you, your organization, your websites, your products or your services.
  - No word mark and/or logo may be used in any way that mischaracterizes any relationship between you and NORD.
  - Vendors may not use any word marks and/or logos to advertise NORD or its members as clients on industry or vendor websites and promotional pieces without NORD’s written permission, and which must be requested in writing.
- All NORD’s logos are distinctive, designed pieces of graphic artwork, owned by NORD. The following usage guidelines must be followed:
  - Do not modify or alter the logos
  - Do not change scale, skew or rotate any logo
  - Do not change the design of any logo
  - Do not change or vary the colors of any logo
  - Avoid screening logos
  - Do not shrink any logo to less than 1” in width or height
  - Do not combine a logo with any other design, trademark, graphic, text or other element, including your name, any trademarks or any generic terms
  - No other design, trademark, text, graphic or other element may be placed closer to a Logo without first meeting the clear space requirements found in the NORD Brand Guidelines
  - Logos may only be placed on solid backgrounds (preferably white) unless approved by NORD, and not over an image or pattern (unless approved by NORD)
  - No artistic effects (such as drop-shadows, gradients or embossing) may be applied
  - No word mark or logo may be used or displayed in any of the following ways:
    - In any manner that, in the sole discretion of NORD, discredits NORD or tarnishes its reputation and goodwill
    - In any manner that infringes, dilutes, depreciates the value, or impairs the rights of NORD in the word marks and/or logos
    - In any manner that is false or misleading
    - In connection with any pornography, illegal activities, or other materials that are defamatory, libelous, obscene, or otherwise objectionable

- In any manner that violates the trademarks, copyright, or any other intellectual property rights of others
- In any manner that violates any law, regulations, or other public policy
- In any manner as part of a name of a product or service of a company or organization other than NORD
- All goodwill generated by the use of any word mark and/or logo inures to the benefit of NORD
- You may not assert rights to any NORD word mark and/or logo whether by trademark registration, common law ownership, domain name registration or anything else
- You must, if requested from NORD, provide samples of any materials that include the NORD word marks and/or logos for purposes of determining compliance with this policy
- You must make any change(s) to your use of the word marks and/or logos that are requested by NORD
- Your download and use of the logos is subject to the NORD Site Terms
- Partners who have agreements with NORD must comply with the terms of their agreement in addition to this policy

NORD Owned Logos:
When downloading and displaying the NORD logos, user agrees to terms outlined in NORD logo policy stated above. For alternate, additional file formats or logo variations, please contact NORD: marketing@rarediseases.org.
NORD OWNED WORDMARKS

Registered (®) Trademarks/Wordmarks:

- NORD®
- NORD logo® (the pinwheel icon)
- National Organization for Rare Disorders®
- Alone we are rare. Together we are strong.®
- Breakthrough Summit® (text and logo)
- Handprints Across America®
- RareAccess®
- RareAction Network® and RAN®
- Rare Action Network® (and logo)
- RareCare®
- RareEDU®
- RareInsights®
- Rare Impact Awards® (text and logo)
- RareLaunch®
- Running for Rare® (text and logo)
- Running4Rare®
- State Report Card® (text and logo)

Pending Patent Office Approval (use TM):

- IAMRARE™ and IAMRARE.ORG™ (wordmarks)
- I AM RARE™ (with spaces)
- Living Rare, Living Stronger™
- Rare Action Road Tour™
- Show Your Stripes™
- Power of Patients™
**APPROVED NORD LOGO USAGE**

**NORD Wide Logo w/Tag**
WHEN TO USE:
White/light backgrounds ONLY.

**NORD Wide Logo No Tag**
WHEN TO USE:
White/light backgrounds ONLY.
NORD’s full name needs to be spelled out somewhere on the piece.

**NORD Logo Stacked w/Tag**
WHEN TO USE:
White/light backgrounds ONLY.
Limitations in art area width, narrow promotional items, social media

**NORD Logo Stacked No Tag**
WHEN TO USE:
White/light backgrounds ONLY.
NORD’s full name needs to be spelled out somewhere on the piece.
Limitations in art area width, narrow promotional items, social media

**NORD Logos [Wide and Stacked] as White**
WHEN TO USE:
Black or extremely dark color backgrounds
- Prints 100% White [or knocks out to white], single gene 50% opacity
- Always have enough contrast between NORD logo and the background color to ensure its legibility
LOGO SAFETY ZONE

Safety zone uses the ‘N’ from logo as a guide.

Dotted rule indicates NORD logo safety zone.

Which version of logo to use?

• PMS and CMYK: Hi-end and multi-colored printed marketing materials (300 dpi/vector art)

• RGB: Digital/screen 72-300dpi, presentations or web/screen applications ONLY (not for printed materials)

PMS Logos:
PMS is short for Pantone Matching System, the printing industry’s standard for specifying ALL solid ink colors. Use for applications that are ink-specific. (i.e.: T-shirts, pens and embroidery).

CMYK Logos:
Also known as process color printing (4-color); using cyan, magenta, yellow and black inks to create the spectrum of color seen in most full color printing. Use on hi-end, multi-colored printed materials. (i.e.: ads, full color communications and posters).

RGB Logos:
A color system based on red, green and blue light, and used to represent the full spectrum of color on video displays.

BW or 1-Color Logos:
Similar to PMS, but uses just a single color. Use for applications that are limited in printing: Embossing, internal office laser prints/faxes and 1-color silkscreened promotions.

REVERSED or WHITE Logos:
These are to be used when the background is black or extremely dark to recognize the traditional NORD orange and blue logo.
NORD LOGO VIOLATIONS

- Drop shadows or pacing a box or circle around NORD logo
- Rearranging NORD logo, change proportions of the elements
- Combining other logos with NORD logo
- Skewing the NORD logo or unauthorized colors
NORD EVENT LOGOS

RARE SUMMIT LOGO
WHEN TO USE:
White/Light Backgrounds ONLY. If placed on a dark background, outline with white rule or glow. Same NORD logo rules apply to this art.

LIVING RARE, LIVING STRONGER
WHEN TO USE:
White/Light Backgrounds ONLY. There is a version for dark-colored backgrounds. Same NORD logo rules apply to this art.

RARE IMPACT AWARDS
WHEN TO USE:
White/light backgrounds ONLY. There is a version for dark backgrounds. Same NORD logo rules apply to this art.

What do the file suffixes mean?
- AI files (Adobe Illustrator) are vector-based artwork.
- EPS files (Encapsulated Postscript) are high-res, vector-based art with transparent backgrounds.
- JPEG files (Joint Photographic Experts Group) are compressed logos on white backgrounds. These are supplied as high-res/300dpi in either CMYK or RGB colors.
- PNG files (Portable Network Graphics format) are digitally-compressed logos with clear backgrounds. These are high-res and can only be saved as RGB (for web or screen/presentations).
NORD PROGRAMS & SUB-BRANDS

NORD® RARE INSIGHTS®

NORD® RARE CARE®

NORD® RARE EDU®

NORD® STUDENTS FOR RARE
NORD PROGRAMS & SUB-BRANDS

NORD®

RARE ACTION NETWORK®

NORD®

RUNNING FOR RARE®

NORD®

RARE CANCER COALITION

NORD®

2019 MEMBER GOLD

NORD®

2019 MEMBER PLATINUM

NORD®

STATE REPORT CARD
Abbreviations
- National Organization for Rare Disorders = NORD®
- District of Columbia = DC (no periods between D and C)
- In medical and academic titles, NORD house style is no periods, so MD, PhD, MPH, etc.

Boilerplate
- About the National Organization for Rare Disorders (NORD®)

The National Organization for Rare Disorders (NORD®) is the leading independent advocacy organization representing the approximately 25-30 million Americans affected by a rare disease. NORD is committed to the identification, treatment and cure of the more than 7,000 rare diseases, of which approximately 90 percent are still without an FDA-approved treatment or therapy.

NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. For more than 35 years, NORD has led the way in voicing the needs of the rare disease community, driving supportive policies and education, advancing medical research and providing patient and family services for those who need them most. NORD is made strong together with over 275 disease-specific member organizations and their communities and collaborates with many other organizations on specific causes of importance to the rare disease community.

Alternate/concise NORD boilerplate:
The National Organization for Rare Disorders (NORD®), an independent nonprofit, is leading the fight to improve the lives of rare disease patients and families. We do this by supporting the rare community, its people and organizations. We work together to accelerate research, raise awareness, provide valuable information and support, and drive public policy that benefits the estimated 25-30 million Americans impacted by rare diseases.

Capitalization
- Headlines: Headline capitalization (first letter of each word capitalized)
- Sub headlines (in newsletters, press releases, etc.): sentence capitalization
- Titles: vanity capitalization. For instance:
  - President and CEO
  - Director of Federal Policy
  - NORD® Member Organizations
  - Board of Directors

Dates, times, numbers
- Dates should appear as Wednesday, February 27, 2019.
- Times should appear as 3:00p.m., or 3:00 - 4:00p.m.
- Phone numbers should appear as 203.304.7289
- Numbers: 1-9 = one to nine; 10 and over should be written out numerically.

Messaging
- Refer to 1/2019 fact sheet for current rare disease facts and sources
- Official NORD mission statement: NORD®, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 275 patient organization members, is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and patient services.

Narrative
- 90% of the over 7,000 rare diseases are still without an FDA approved treatment, with an average of 5-7 years for an accurate diagnosis. NORD is committed to changing that by:
  - Raising awareness of rare diseases
  - Ensuring patients and families are empowered to be their own advocates
  - Aiding medical professionals with resources to facilitate earlier diagnosis and more timely treatment
  - Educating the public on the challenges associated with rare diseases and orphan drugs
Concise copy that can be used to describe key NORD areas of focus:

- **Education** - NORD® and its members are leading a multi-front campaign to promote earlier diagnosis, optimal care and awareness of rare diseases. We run educational programs for patients and caregivers, medical professionals, students and other stakeholders.

- **Events** - We bring the entire rare community together at programs held throughout the year, including the NORD® Rare Summit and the Living Rare, Living Stronger Patient and Family Forum.

- **Membership** - NORD® provides mentorship, education and support to more than 275 disease-specific patient organizations and over 10,000 individual advocates. NORD is also home to the Rare Cancer Coalition, a unique group of advocates working collaboratively to lead the charge against rare cancers.

- **Patient Assistance** - NORD provides financial assistance to eligible patients and families struggling to obtain life-saving or life-sustaining treatment and care. NORD’s RareCare™ programs assist both adult and pediatric patients diagnosed with a wide range of disorders and include medication, insurance premiums and co-pays, diagnostic testing, caregiver respite grants and travel assistance to treatment sites and clinical trials.

- **Policy and Advocacy** - NORD® advocates for the rare community at the state and federal levels through our Rare Action Network®. We represent the voice of patients to advance basic and translational research, strengthen the drug development process and ensure access to affordable treatment.

- **Research** - NORD® is accelerating research into treatments and cures through natural history studies, the IAMRARE™ program, as well as research we fund and conduct.

**Miscellaneous**

- NORD® adheres to AP style for copy and AMA for citations.
- No Oxford commas are to be used, unless explicitly needed for clarity in a sentence.
- ONE space between a period and beginning of a new sentence is correct.
- Spelling, grammar and punctuation checks are done more rigorously and reliably in MS Word than in Google docs.
- Beware of formatting changes when downloading a Google doc to MS Word.

**Voice and tone**

The overall voice of NORD® as an organization can be summed up in four P’s: positive, passionate, professional and above all, patient-centric.

NORD is an approachable leader in the rare disease space and a multi-faceted organization made up of caring, compassionate people and groups. We are responsive, effective, inclusive and informative.

- Voice variations (by NORD event)
  - **Event description:** Living Rare, Living Stronger NORD Patient and Family Forum is a special gathering of people living with rare diseases and their families, the medical professionals, advocates and other supporters working to help improve their lives. Patients and families can gain insights and make connections through educational sessions and discussions created just for them, with lots of fun for kids and adults alike.
  - **Voice:** warm, welcoming, inclusive, informative, fun, playful yet professional

  Event description: Held annually in Washington, DC, the NORD Rare Diseases and Orphan Products Breakthrough Summit is the largest multi-stakeholder event in rare diseases, presenting two days of timely, impactful panels, breakout sessions and networking opportunities for attendees that include senior FDA staff and other government officials, patient advocacy group leaders, industry representatives, healthcare providers and others.
  - **Voice:** inclusive, informative, authoritative, timely, serious

  Event description: The Rare Impact Awards is an annual awards program at which NORD honors those individuals, groups and companies making great strides to improve the lives of people living with rare diseases.
  - **Voice:** celebratory, fun, professional
IMAGES

The photographs used in any marketing materials must convey the positive and upbeat personality of NORD’s brand. The images should be bright and vibrant. Candid photography cropped tightly with soft focus; showing patients interacting is preferred over posed photographs, especially when shown in marketing materials.

Photographs should never be dark, sad or manipulative. While we will be showing images of patients who are affected by a rare disease, these pictures should portray them during moments of happiness – when they are getting the assistance NORD is offering them. Look at how we help improve lives within the rare disease community. Images should “feel” hopeful – not distressed, dark or weepy.

The patient’s name and condition should always be noted; preferably at the bottom left or right of the image.
ADVERTISING

The editorial voice is honest, visionary, smart and caring. We seek to foster an emotional connection between the viewer and the NORD brand. Therefore it must contain life and elicit a reaction.

Visuals and type should not compete, but support each other. We are direct and confident, bold yet not boastful. We speak conversationally. We have a strong voice that understands patient needs, leads changes and commands trust in the Rare Disease Community.
EVENT DISPLAYS

Panels are designed 2-sided to stand alone or altogether.
[3’x8’ and 10’x 8’ fabric panels]
STATIONERY (business card)

Suggested business card for NORD

**FRONT:**
- NORD Logo prints 100% PMS 1665 and PMS 313
- Text prints 100% PMS 413
- Font: Myriad Pro Regular and Bold

**BACK:**
- NORD Logo prints 12% PMS 1665 and PMS 313
- Orange text prints 100% PMS 1665
- Blue ‘Rare’ text prints 100% PMS 313
- Font: TradeGothic 20 Bold Condensed
Date of Letter

Recipient’s name
Recipient’s title
Recipient’s company
Recipient’s company address

Recipient’s Name:

People read business letters quickly. Therefore, get to the point in the first paragraph—the first sen-
tence, if possible. In other words, state what you want up front.

Single space your letters and use a serif typeface. Skip a line between paragraphs. Because people
read business letters quickly, use shorter sentences and paragraphs than you would in a longer docu-
ment. Sentences should average fewer than twenty words, and paragraphs should average fewer than
seven lines.

Space your letter on the page so that it does not crowd the top. However, if possible, keep your letter
to one page. Second pages often are not read. Send copies to anyone whose name you mention in the
letter or who would be directly affected by the letter.

Final paragraphs should tell readers what you want them to do or what you will do for them.

Sincerely,
Signature
Name

Enclosure

cc: Name to receive copy
#9-1/2 BOOKLET ENVELOPE (12” x 9”) w/FLAP NO 12” SIDE:
• NORD Logo prints 100% PMS 1665 and PMS 313

#10 STANDARD ENVELOPE (9.5” x 4.125”):
• NORD Logo prints 100% PMS 1665 and PMS 313
• Flap Text prints 100% PMS 1665
DIGITAL MEDIA (email)

EMAIL SIGNATURES:
• Customize based upon the SOP for NORD Email Signatures
• Special promotions placed at the end of the legal statement
• Emails should be written in San Serif font (Size: Normal) for consistency

Recipient's Name:

People read business letters quickly. Therefore, get to the point in the first paragraph—the first sentence, if possible. In other words, state what you want up front.

Single space your letters and use a serif typeface. Skip a line between paragraphs. Because people read business letters quickly, use shorter sentences and paragraphs than you would in a longer document. Sentences should average fewer than twenty words, and paragraphs should average fewer than seven lines.

Best,
Name Here
CONTACT

For questions and requests regarding the NORD® brand components, please contact our Marketing Department:

Lesli Nordstrom, Director of Marketing and Communications
lnordstrom@rarediseases.org

Lisa M. Sencen, Senior Creative Designer
lsencen@rarediseases.org

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55 Kenosia Avenue
Danbury, Connecticut 06810
Telephone: 203-744-0100
Fax: 203-263-9938

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Quincy, MA 02169
Phone: 617-249-7300
Fax: 617-249-7301

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1779 Massachusetts Avenue, Suite 500
Washington, DC 20036
Phone: 202-588-5700
Fax: 202-588-5701