



NORD and Coronavirus: Business Continuity Response for RareCare® Patient Assistance Programs

In these unprecedented times, the National Organization for Rare Disorders® (NORD) is taking necessary steps to ensure the well-being of the patients we serve, as well as our vendors, partners and employees. The following information is provided to underscore NORD's commitment to the rare disease community and relay the processes we have instituted for business continuity, to date.

Business Continuity Plan:

Effective March 18, NORD implemented telecommuting for our entire staff across our three offices in Connecticut, Massachusetts and Washington, DC, for the foreseeable future. NORD's RareCare® Patient Assistance Programs and call center are fully accessible for remote work. As a result, there is no disruption to our services or hours for these programs.

For staff, remote preparations included issuing individual laptops with secure data access. All production systems are hosted and backed up on the cloud with redundancy. When alternate office space may be needed, we have local hotel partners to assist. In the event of government-issued stay at home orders, NORD will direct mail to be forwarded to an alternate address so that business may continue as usual. We will use our website and email system for communications and updates.

Understanding that there may be significant increases in online meetings and demands on internet bandwidth, NORD's IT team is in touch with our technology providers to minimize any potential disruption to NORD's services. Backup plans are in place, if required. We will monitor our programs for any issues and seek to mitigate effectively and efficiently.

Events:

Like organizations worldwide, we have postponed all public events, with our next public event tentatively scheduled for October. We will evaluate future events as necessary.

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At NORD, we have always been innovators in the face of challenges and we remain hopeful for the future. Our staff continues to work with urgency to move our programs forward to help rare disease patients and families. Our management team is monitoring the situation so that we remain flexible and responsive to the needs of our community. We will continue to provide information and resources throughout this uncertain time. As always, thank you for your support.

Alone we are rare. Together we are strong.®

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