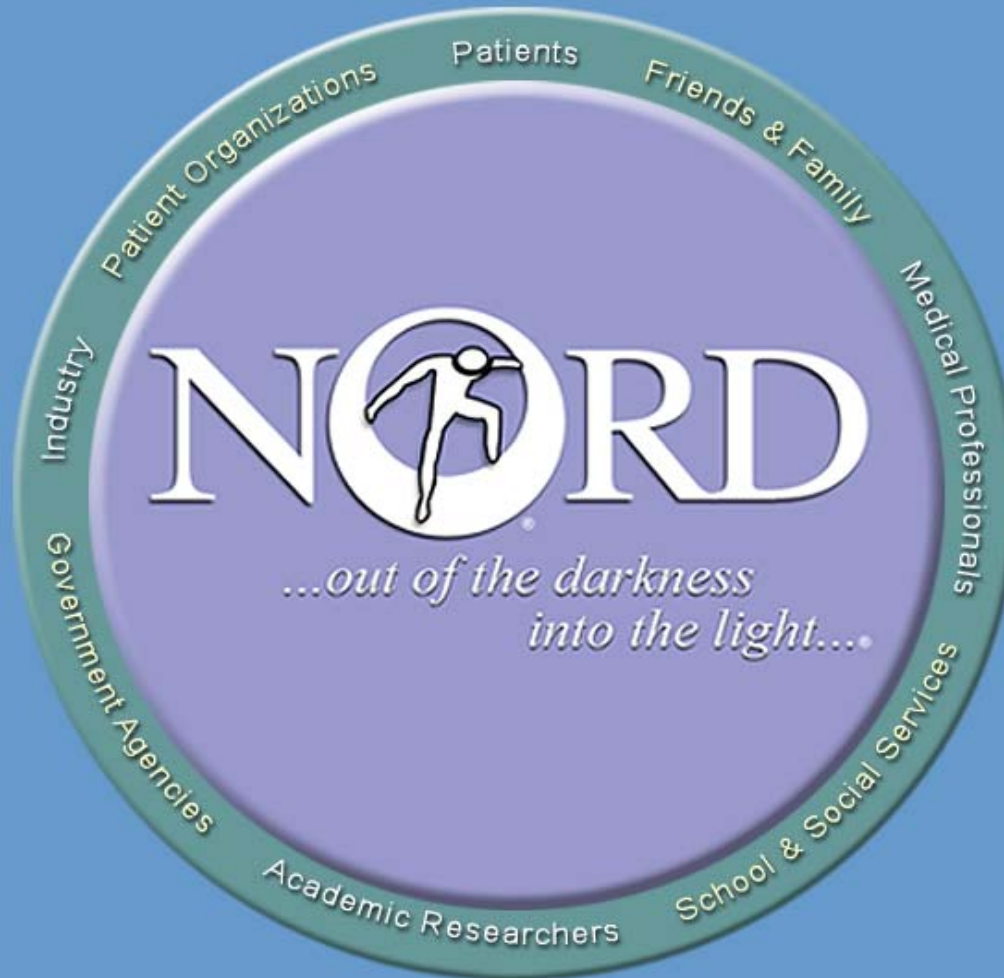


Access to Information and Orphan Products: The NORD Experience



NORD is in a unique position to help, because it serves as a hub of communication for all involved.

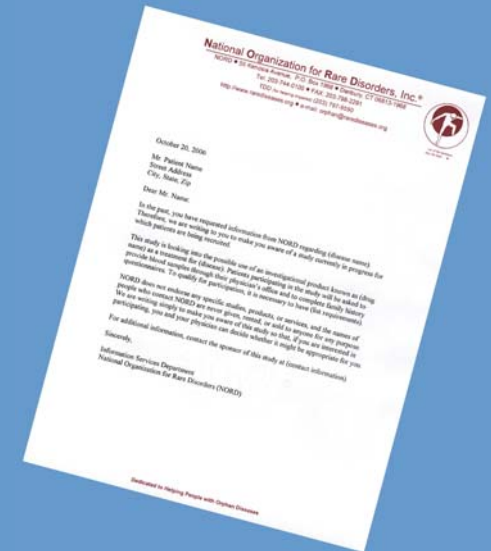


NORD helps researchers in government, industry, and academia with patient recruitment.

- We publicize clinical trials on our Web site and in our newsletter.
- Each of the 1,200 reports in NORD's Rare Disease Database has a section on current investigational therapies.
- We mail "Clinical Broadcast" letters to patients and families to notify them of clinical trials.

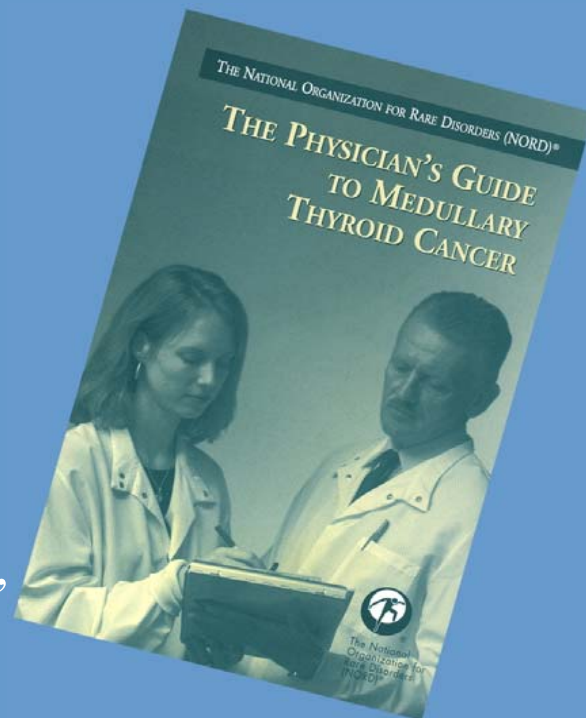
“Clinical Broadcasts” are letters we send to people who have requested information on specific rare diseases.

- On NORD letterhead
- Sent to patients and families from NORD’s main database
- NORD doesn’t endorse studies
- Sponsors review letters beforehand
- NORD honors its promise to patients never to give, rent or sell their names to anyone



We provide information to medical and other professionals.

- Free *Physician's Guide* booklets
- Five annual medical meetings
- Nurse and genetic counselor on staff are in frequent contact with school nurses, social workers, teachers, and other professionals
- Subscription and licensing agreements
- NORD's role is to provide brief introduction, with referrals to other resources for more information



We help pharmaceutical and biotechnology companies provide access to orphan products.

- Medication assistance for uninsured
- Insurance co-pay programs
- Early or expanded access to investigational products
- Emergency or limited access to products in short supply
- Travel and relocation assistance for clinical trial participants
- More than \$63 million in free drug and \$9 million in co-pay assistance (2006)

NORD works directly with patients, their families, and patient organizations in many ways.

- Information center (refer to GARD and patient organizations)
- Nurse and genetic counselor on staff (RN@rarediseases.org and genetic_counselor@rarediseases.org)
- Nonprofit Resource Center for patient organizations or those wishing to start one
- Networking, both traditional and online



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NORD Rare Disease *Support Community*



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About us

NORD Rare Disease Support Community

About this group

The NORD Rare Disease Support Community connects patients, families, friends and caregivers for support and inspiration. The NORD Rare Disease Support Community is sponsored by the National Organization for Rare Disorders in partnership with Inspire.



Contact

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A sampling of topics from NORD's online community:

- One member posted a notice describing a particular type of dwarfism and asked, “Are there others out there with this disorder?” Responses included information about a support group and patient registry.
- The leader of a small patient organization asked for, and received, advice related to writing grant applications.
- Ed Boyer, of Mercy Medical Airlift, posted a notice about free long-distance medical air transportation.
- All postings must be non-commercial in nature.

On this 25th anniversary, NORD's future plans include even greater emphasis on:

- Internationalism
- Online networking
- Partnership



