Paving the Path for Access to Treatment and Care

Catherine Blansfield
Vice President, Patient Services
NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.
NORD

An independent charity established by patients and patient advocates who mobilized support for the passage of the Orphan Drug Act of 1983.

• 7 years of marketing exclusivity
• 50% tax credit on costs related to orphan drug clinical research
• Federal grants for orphan product development
Orphan Drug Act: Current Day Progress

Number of Approved Orphan Products by Year

Year


Number of Products

0 10 20 30 40 50 60

2 3 8 6 9 10 11 13 15 15 11 11 18 26 26 20 15 14 13 13 20 24 20 16 17 20 15 26 26 33 48 41
NORD Patient Assistance, Today

• 30 years of white glove assistance
  – Across the service continuum
  – Across the disease continuum
• Technology investment
  – Electronic services
  – RareAccess™ Portal
  – RareCare™ 5th generation case management system
• Human capital investment
  – Leadership and staff
Disease Centric Design

- Pharmaceuticals
- Labs
- Clinic Visits
- Diagnostics
- Biologics
Patient Centered Approach
RareCare® Patient Assistance Programs

• Patient Financial Assistance
  – Premiums, copays, and coinsurance
  – Copay cards
    • Single therapies
    • Generics
  – Diagnostic testing
  – Ancillary medical services
  – Emergency relief funds
  – Travel and lodging
  – Clinical trial support
  – Expanded Access Programs

• Information & Referrals
Program Administration

NORD Team

- On-going Follow Up with Patient
- Application Submission
- Award Decision & Notification
- Coordinate Access to Services
- Bill Processing & Monthly Reporting
- EIV Approvals
- Voice Recordings

RareAccess™ Portal
General Provisions

• Patients can self refer, be referred by a physician or a manufacturer’s hub

• Patients can apply and receive assistance from multiple programs

• Awards are granted on a calendar year basis

• Patients are encouraged to reapply

• Patients qualified for support should feel confident that adequate funding has been secured by NORD to pay for qualified expenses
General Requirements

• Diagnosed or under consideration/evaluation for the diagnosis
• US citizenship or permanent US residency status
• Signed application and supporting financial documentation
• Valid prescription, where applicable
• Signed HIPAA consent form
Financial Eligibility

Two Tiered Approach

1. **Electronic Income Verification (EIV)**
   - % of FPL evaluation
   - Over the telephone
   - No documentation to submit
   - Immediate feedback

2. **Financial Means Test**
   - Safety net for those who do not pass % FPL
   - Documentation required
   - Full income to expense evaluation conducted
Electronic Income Verification

- Secure website source for credit information
- Award decisions can be made within 5-10 minutes of patient engagement
- Permissions are verbally recorded and digitally stored
• Debit/Credit Cards
  • Elimination of upfront/out of pocket costs for patients for covered services
    – Travel
    – Food
    – Insurance premiums
    – Copay payments
Data Sources

Patients and Caregivers
Advocacy Organizations
Case Managers
Site Coordinators
Insurance Agents and claim forms
Pharmacies
DME Companies
Laboratories
Other Vendors
  • Travel
  • Lodging
Online System offering convenience and easy access for patient referrals from Specialty Pharmacies and Case Managers

- Disease Program Specific
- Patient Demographics
- Insurance Information
- Physician Name and Contact Information
- Pharmacy Information
- Diagnosis Confirmation
  - CMN
  - RX
- Other Notations/Need to Know Information
- Two Way Communication between Referring Entity and NORD

rarediseases.org
Insurance Planning 101

- 1:1 PSR: Patient
- Webinars
- User friendly educational materials
  - Video series
Insurance Timing

- Open Enrollment Periods
  - November 1, 2017 - **December 15, 2017**
  - Formerly - until January 31st
- Reduced to 45 days**
- Reenrollment is automatic
- “Reduce opportunities for adverse selection”
  - Healthy procrastinators
  - Plan switching among re-enrollees
Program Contact Information
Narcolepsy Copay Assistance Program

Toll Free Phone
1-855-202-5826

Fax
1-203-405-8795

Email
narcolepsy@rarediseases.org
Proactive Solutions for Sustaining Innovation and Ensuring Patient Access

• Coalition Building
  • NORD membership groups
  • Patient engagement
• Drug Development
  • Guard against dilution of rare disease considerations as synonymous with common disorders
• Equal Opportunity to Medical Care
  • Physician Education
  • Adequate, Affordable Insurance
  • Patient Assistance Services
Thank you.

Alone we are rare. Together we are strong.

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