



Wednesday, March 20, 2024



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Today's Speakers

Agenda

A Few Definitions

URAC's Expertise in Rare Disease

Discussion with URAC Rare Disease
Pharmacy Reviewers

Questions



What is a Rare Disease?

- A condition that affects fewer than:
 - 200K people (US definition)
 - One in 2,000 people (European Union definition)
- Rare diseases became known as ***orphan diseases***; drug companies lacked incentives to develop treatments
- Orphan Drug Act created ***financial incentives*** to ***encourage new drug development*** for rare diseases

There are more than 10,000 known rare diseases that affect about 1 in 10 people (or 30 million people) in the U.S.

Source: <https://rarediseases.info.nih.gov/diseases/pages/31/faqs-about-rare-diseases>

What is an Orphan Drug?

Per the Orphan Drug Act: a special status granted to a drug or biological product (“drug”) to treat a rare disease or condition

What is a Rare Disease Pharmacy?

A pharmacy that clinically manages patients taking an orphan drug

URAC is the Leader in Specialty Pharmacy Accreditation

Our Clients

Specialty Pharmacies
Community Pharmacies
Mail Service Pharmacies
Infusion Pharmacies
Vaccine Providers
Hospitals
Health Plans
Telehealth Providers
Utilization Management
Credentials Verification
Health Websites

URAC Specialty Pharmacy Accreditation



Payers and manufacturers have recognized the value of accreditation and often require SPP Accreditation for network participation or access to limited distribution drugs

URAC Rare Disease Pharmacy Center of Excellence Certification

2020

19

v3.0



Recognizes **pharmacists' critical role** in the management of individuals living with rare disease and **positions and elevates** specialty pharmacies that wish to contract with rare disease manufacturers

URAC's Rare Disease Pharmacy
Center of Excellence Certification
standards build upon the Specialty
Pharmacy Program **Patient
Management** Focus Area

RD-PM 1:
Rare Disease Patient Management
Program Overview

RD-PM 2:
Rare Disease Assessments

RD-PM 3:
Rare Disease Education and
Support

RD-PM 4:
Rare Disease Care Team
Collaboration

RD-PM 5: Program Evaluation
and Review

Discussion with URAC's Rare Disease Accreditation Reviewers

Questions



Connect with URAC

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