

Medicare Prescription Drug Benefit Position Paper

Background

The National Organization for Rare Disorders (NORD) is delighted that Congress is working diligently to develop legislation creating a long-overdue Medicare prescription drug benefit for seniors and just as importantly, disabled Americans of all ages who are unable to work.

As you deliberate the type and scope of a prescription drug program, we ask you to remember the needs of people with rare health conditions (known as “orphan” diseases) who sometimes require treatments that are extraordinarily expensive, and thus can be financially devastated by the high cost of “orphan” therapies to treat those rare diseases. Large deductibles and co-payments, including co-payments even after a “catastrophic” limit is reached, will be financially devastating for rare disease patients. Their care is not a matter of choice; it can be a matter of life and death.

In 1983 Congress enacted the *Orphan Drug Act*, which provides financial incentives to encourage pharmaceutical and biotechnology companies to develop treatments for small populations of people with serious and life-threatening diseases. Today there are 242 orphan drugs to treat such rare diseases such as narcolepsy, severe combined immune deficiency, hemophilia, amyotrophic lateral sclerosis (Lou Gehrig’s disease), cystic fibrosis and multiple sclerosis. Because few people use these drugs, they tend to be more expensive than treatments for common diseases, but they are lifesaving and life-enhancing therapies.

Policy Position

- Every senior citizen, and every person with a disability who is enrolled in Medicare, should be provided with guaranteed, affordable and comprehensive prescription drug benefits under Medicare.
- Rare disease Medicare beneficiaries should have pharmaceutical insurance benefits at least equivalent to the average privately insured American who receives their health insurance through their employer or through the Federal Employees Health Benefits Program (FEHBP). There should be no coverage gap that exposes beneficiaries to large out-of-pocket costs.
- There should be no co-payments required once a beneficiary reaches an expenditure level that would trigger a catastrophic benefit. This is particularly important for rare disease patients whose therapies can cost \$100,000 or more. After a rare disease patient has reached the threshold for catastrophic coverage, the program should cover 100 percent of the cost of drugs.
- The benefit should include significant protection for the most vulnerable beneficiaries. These protections should include significant reductions in, or elimination of, premiums, co-payments and deductibles.
- If a prescription drug benefit is administered by the private sector, the federal government must be prepared to offer pharmaceutical benefits directly if the private sector fails to offer an affordable, reliable and acceptable benefit.
- There should be an appeals process that ensures that physicians can override the formulary when medically appropriate.

For More Information...

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