CAP THE CO-PAY ON SPECIALTY TIER MEDICINES

Several states are considering legislation to tackle high cost-sharing for specialty and orphan medications. Currently, people with rare diseases are forced to pay as upwards of $1,000 per month in co-pays because their medicines are placed on a so-called “specialty tier” formulary. Proposed legislation would mandate a cap on out of-pocket costs for specialty medications. These caps range from $100 to $200 per month per specialty medication. NORD supports these initiatives, and has joined several state-based coalitions to help pass these bills.

RARE DISEASE ADVISORY COUNCILS

NORD supports the goal of creating a State Rare Disease Advisory Council. At the request of our members, we have drafted model legislation that incorporates the core provisions of existing proposals while ensuring patient input and outside coordination is a priority. Specifically, NORD’s model legislation would require the following:

- Persons with rare diseases are strongly incorporated into council membership.
- The work of rare diseases councils is coordinated with other rare disease advisory bodies, state and federal agencies, and community-based organizations.
- States thoroughly examine the feasibility of operating stand-alone rare disease registries before mandating their creation. And if states do choose to create a registry, that it is coordinated with other state and federal research efforts.

OTHER STATE PRIORITIES

NORD and its members continue to support state policies that improve care for persons with rare diseases. For example, many state advocacy coalitions have proposed legislation to expand newborn screening to new diseases, as well as to ensure greater access to Medical Foods. NORD will continue to monitor and engage on these priorities with our members and partner coalitions.

Follow @RareDiseases and @RareDayUS
Use the hashtags #RDD2015 #RareDiseaseDay

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