

# NORD Press Release

The Institute of Medicine (IOM) today released a report calling for implementing an integrated national strategy to promote rare diseases research and product development. The report, *Rare Diseases and Orphan Products: Accelerating Research and Development*, is the result of a two-year study commissioned by the National Institutes of Health (NIH) and the Food and Drug Administration (FDA).

The full text of the report is available on the IOM website.

<http://www.iom.edu/Reports/2010/Rare-Diseases-and-Orphan-Products-Accelerating-Research-and-Development.aspx>

As a key stakeholder in the rare disease community, the National Organization for Rare Diseases (NORD) provided input to IOM for this report.

NORD President and CEO Peter L. Saltonstall today issued the following statement:

"The IOM report contains many recommendations that NORD advocates and endorses. On the regulatory and discovery front, NORD is working closely with the FDA and NIH to help implement many new initiatives. Earlier this year, for example, NORD established a task force with the FDA and NIH to achieve many of the objectives identified by the IOM report. The report provides further support for these joint efforts.

"NORD especially endorses the IOM recommendations that would seek to assure better access by patients to new therapies and a compendium that would recognize that some therapies used by patients with rare diseases are not formally approved by the FDA for that use. Assuring access to existing and new therapies is a top priority, and we are pleased that the report recognizes that patients with rare diseases often face special challenges regarding access."