|  |  |
| --- | --- |
|

|  |
| --- |
| NORD_Logo_wTag_Web_RGB.png |

 |

|  |  |
| --- | --- |
|

|  |
| --- |
| **NORD Issues Statement as Senate Postpones Vote on Cures Legislation** |

 |

|  |  |
| --- | --- |
|

|  |
| --- |
| **Washington, D.C., July 14, 2016** – The following statement was issued by Peter L. Saltonstall, President and CEO of the National Organization for Rare Disorders (NORD), as the Senate announced it would not vote on its Cures legislation, also known as the Senate Innovations for Healthier Americans Initiative, until September at the very earliest. *“On behalf of the 1 in 10 Americans with rare diseases, most of whom are still waiting for a treatment or cure, we are disappointed that Senate Cures was not able to pass at this point.  We will keep pushing for this legislation through the summer recess and into September to ensure the voices of patients and families are heard.**Many people with rare diseases are in a race against time.  There are 7,000 rare diseases and 95 percent of these have no treatment.  This public health issue encompasses cancer—approximately half of people with cancer are battling a rare cancer—and neurological, metabolic, digestive, blood and other disorders that are present across the medical spectrum.**This vital package includes billions of dollars to spur medical innovation that would help the rare disease community, including new funding for critical research at the National Institutes of Health (NIH) and to accelerate drug approval at the Food & Drug Administration (FDA), and other provisions such as the OPEN ACT and Vice President Biden’s Cancer Moonshot, with the potential to stop rare diseases from altering and ending the lives of too many Americans far too soon. Most pressing is the reauthorization of the Rare Pediatric Disease Priority Review Voucher program currently set to expire at the end of September.”*Peter L. SaltonstallPresident and CEO, National Organization for Rare Disorders (NORD) |

 |