



Support Robust Funding for NIH and FDA

Please support an increase in annual funding for the **National Institutes of Health (NIH)** in the Fiscal Year 2020 Labor, Health and Human Services, Education Appropriations Act. Please also support an increase in funding for the **Food and Drug Administration (FDA)** in the Fiscal Year 2020 Agriculture Appropriations Act. While Congress has provided the NIH and FDA with crucial funding increases in recent years, the NIH is still forced to turn away 80% of the promising research grant proposals it receives, and FDA resources are stretched dangerously thin as it works on multiple fronts to speed medical progress and protect the public health. There is no doubt that insufficient funding slows desperately needed progress against rare diseases. **It is estimated that 1 in 10 individuals has a rare disease. There are an estimated 7,000 rare diseases, but unfortunately the vast majority – over 90 percent – do not have an FDA-approved treatment.**

National Institutes of Health (NIH)

- NIH is the world's leading funder of basic biomedical research, supporting breakthroughs in how we understand and treat deadly and debilitating diseases.
- More than 80 percent of the NIH funding is spent outside its own laboratories through competitive grants to researchers at more than 2,500 universities, medical schools, and other research institutions, with a presence in all 50 states.
- The NIH also trains next generation researchers, participates in public-private partnerships aimed at breaking through costly gridlock at every stage of the research and development process, and supports the undiagnosed diseases network, which is crucial to helping patients facing ultra-rare and other elusive health threats.
- Every dollar invested in research by the NIH generates an estimated \$2.20 in local economic growth.

Food and Drug Administration (FDA)

- The FDA plays a critical role in putting cures into the hands of patients through the review and approval of innovative treatments and devices.
- Increased funding supports the infrastructure and staff that move products through the review pipeline.
- Expanded resources allow FDA to conduct this often-lengthy process more quickly, ultimately lowering costs, increasing safety and bringing treatments to patients sooner.
- This funding supports rare disease and orphan drug initiatives that have yielded vital new treatments.
- The products FDA oversees account for 20 cents of every dollar spent by U.S. consumers.

Rare Disease Legislative Advocates (RDLA), a program of the Everylife Foundation for Rare Diseases, works to empower the individual to become an advocate by providing informational meetings, legislative resources, advocacy tools, and special events that support organizations and advocates working to promote rare disease legislation. RDLA's objective is to grow the patient advocacy community and work collectively to ensure that patients have a voice on Capitol Hill.

Please contact Shannon von Felden (vonfelden@curetheprocess.org) to learn more about RDLA.

Research!America informs leaders, policymakers and the public about the critical role research plays in keeping America competitive, alive and well. The organization works to ensure research funding and growth.

Please contact Ellie Dehoney (edehoney@researchamerica.org) to learn more about Research America.