



July 19, 2022

The Honorable Patrick Leahy
United States Senate
437 Russell Senate Office Building
Washington, DC 20510

The Honorable Richard Shelby
United States Senate
304 Russell Senate Office Building
Washington, DC 20510

Dear Chairman Leahy and Ranking Member Shelby,

On behalf of Patients Rising Now, we would like to thank you for your hard work as members and leaders of the Senate Appropriations Committee and congratulate you both on your long, distinguished careers. The work you have done on this Committee has been integral in ensuring that health-related agencies have the level of funding necessary to maintain and increase patient access to critical treatment and we are extremely appreciative.

Formed in 2015, Patients Rising Now has developed a significant following of over 110,000 patients and caregivers and has guided them on their journeys to advocate for themselves and their loved ones to get the care and treatments they need to live a fulfilling life. As a patient advocacy organization, we support reforms and legislation aimed at advancing patient access to affordable, quality healthcare. For this reason, we request that you match the levels of funding for HHS and FDA set by your colleagues in the House in your coming Appropriations bills.

The House Appropriations Committee advanced both their HHS and FDA funding bills to the House floor recently. The amounts appropriated for each represent \$15,593,727,000 (~14.4%) and \$341,565,000 (~10.3%) increases in funding from FY22 respectively. Additionally, the introduced Defense package makes available \$1,144,000,000 for the Congressionally Directed Medical Research Programs: these critical programs make innovation and treatments possible for rare and chronic disease patients. These apportioned figures represent the strong and continued momentum for which patient advocates have long been calling.

Within the HHS bill, there are large allotments for Chronic Disease Prevention and Health Promotion (\$1,601,914,000). The purpose of this funding is to promote prevention and control of chronic diseases. Further in this bill, there exists similar language regarding rare disease patients, but no appropriated funds as yet. While there are appropriations for specific rare diseases, as well as calls for increased support of the Rare Disease Clinical Research Network and a CMS report on the barriers rare disease patients experience when seeking treatment, more broad rare disease funding seems to have stalled.

We would like to see establishment of a Federal Rare Disease program similar to what currently exists for chronic diseases. Rare and ultra-rare diseases are often left out of health policy discussions because the path to treatment is more complicated than other disease states. Congressional funding to both encourage research and improve awareness of rare and ultra-rare diseases would make a world of difference in the pursuit of treatments and cures.



We strongly favor the House's continued support for these integral programs, and we thoroughly encourage you and the Senate Appropriations Committee to follow suit.

cc: Members of the House and Senate Appropriations Committees

Sincerely,

A handwritten signature in black ink that reads "Terry Wilcox". The signature is written in a cursive style with a large, prominent initial "T".

Terry Wilcox
Executive Director