November 25th, 2016

The Honorable Elizabeth Warren  The Honorable Edward Markey
United States Senate United States Senate
Washington, D.C. 20510 Washington, D.C. 20510

Dear Senators Warren & Markey:

We write today as members of the Massachusetts academic community to request your support for a vital piece of legislation, the Orphan Product Extensions Now, Accelerating Cures and Treatments (OPEN ACT) S. 1421.

This legislation would provide a needed incentive to repurpose existing therapies for rare disease indications. In doing so, this bill could provide hundreds of new and relatively low-cost treatment options for the 30 million Americans with a rare disease by leveraging the work already done in so many treatments. As it stands, 95% of the 7,000 rare diseases have no FDA-approved treatments. This bill will be the fastest and most efficient way to get more rare disease patients treated.

In addition to providing new treatment options to patients, this bill would require extensive clinical testing and research studies in order to gain FDA-approval for a new indication. Such clinical studies would be carried out at academic medical centers across the Nation and at the top research centers here in Massachusetts, providing a substantial infusion of research dollars to undertake needed studies. This new investment would help create high-quality, research-intensive jobs that would play a key part in uncovering new therapy options for rare disease patients and would complement your efforts to increase NIH funding, which we support and applaud.

Thank you for your leadership and support for research and innovation here in Massachusetts and across America. We hope we can count on your support for the OPEN ACT S. 1421.

Sincerely,

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United States National Medal of Technology and Innovation (2011)
Wolf Prize in Chemistry (2013)
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