

March 12, 2020

The Honorable Nancy Pelosi
Speaker, United States House of Representatives
1236 Longworth House Office Building
Washington, D.C. 20515

The Honorable Mitch McConnell
Leader, United States Senate
317 Russell Senate Office Building
Washington, D.C. 20510

The Honorable Kevin McCarthy
Minority Leader, United States House of Representatives
2468 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Charles Schumer
Minority Leader, United States Senate
322 Hart Senate Office Building
Washington, D.C. 20510

RE: Potential Aid for Industries Impacted by Coronavirus

Dear Speaker Pelosi and Leaders McConnell, McCarthy, and Schumer:

We are writing regarding prospective federal intervention to support the airline, travel, and other targeted industries impacted by the coronavirus (COVID-19) epidemic. Hemophilia Federation of America, the National Hemophilia Foundation, and 33 of our member organizations, chapters, and affiliates urge you to also include patient advocacy organizations and similar non-profits within any federal aid packages or supplemental appropriations measures. Many of these organizations have been and will be harmed by event cancellations, travel restrictions, and decreased giving caused by economic uncertainty as a result of COVID-19. Because of our tax-exempt status, this may necessitate targeted assistance or reshaping tax code-related assistance.

Hemophilia Federation of America is a national community-based, grassroots advocacy non-profit that assists, educates, and advocates for people with hemophilia and other bleeding disorders. HFA is dedicated to the cause of improving care and quality of life for all people with bleeding disorders by removing barriers to diagnosis, treatment, and cure. As a federation, our membership includes not only individual members, but also 50 local non-profit patient advocacy organizations that represent individuals and families affected by bleeding disorders. The National Hemophilia Foundation is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research. Established in 1948, NHF has 51 affiliated chapters throughout the country.

The spring season is a time when HFA, NHF, our chapters and member organizations, and so many other patient advocacy organizations hold important events that drive a significant portion of our revenue. HFA's annual Symposium, to take just one example, typically draws over 1300 in-person attendees, and

historically accounts for almost \$2 million of our annual operating revenue. HFA's 2020 Symposium was slated to take place in late April; due to the fast-spreading COVID-19 epidemic, we are currently trying to reschedule it for later in the year. HFA, NHF, and many of our affiliated organizations are also cancelling or postponing numerous other events that entail in-person attendance at convention centers, hotels, and other event facilities. All of our organizations anticipate losing important revenue that we count on to support people with bleeding disorders; we also face the real prospect of forfeiting significant non-refundable expenses already promised to hotels, conference centers, and vendors.

HFA, NHF, and our affiliated organizations are also concerned by potential impacts on individual and corporate giving in a time when health-related organizations are most needed. Congress should ensure communities are able to support their local nonprofits during this crisis by enacting a targeted, temporary giving incentive that enables all residents, regardless of whether they claim itemized deductions, to receive a tax incentive for giving to the work of charitable nonprofits responding to, or suffering from, the coronavirus.

Additionally, our organizations operate similarly to small businesses and are greatly impacted if employees are forced to take sick leave or are quarantined as a result of COVID-19 interactions. We are aware that the Administration and Congress are considering measures for small businesses and impacted industries that may require cash flow assistance amid the outbreak, and urge that tax-exempt entities be included in any temporary aid designed to stem the economic fallout resulting from COVID-19. If Congress does intend to focus relief or stimulus legislation on tax relief, it must expressly apply to employment at tax-exempt organizations by making tax credits and deductions applicable to those taxes that non-profits do pay.

As patient advocacy organizations, HFA, NHF, and our members, chapters, and affiliates stand ready and able to assist Congress and the administration in combating the COVID-19 outbreak in addition to meeting our mission to serve people with bleeding disorders – but we need to be sure that we can remain financially stable through the upcoming financial uncertainties.

Thank you for your consideration.

Sincerely,

Hemophilia Federation of America
National Hemophilia Foundation
Coalition for Hemophilia B

Arizona Bleeding Disorders
Bleeding Disorders Alliance of Illinois
Bleeding Disorders Alliance of North Dakota
Bleeding Disorders Association of Northeastern New York
Bleeding Disorders Association of Southern Tier
Connecticut Hemophilia Society
Florida Hemophilia Association
Gateway Hemophilia Association
Great Lakes Hemophilia Foundation
Hemophilia Alliance of Maine
Hemophilia Association of the Capitol Area

Hemophilia Association of New Jersey
Hemophilia Council of California
Hemophilia Foundation of Northern California
Hemophilia Foundation of Michigan
Hemophilia Foundation of Minnesota/Dakotas
Hemophilia Foundation of Southern California
Hemophilia of New York
Hemophilia of North Carolina
Hemophilia of South Carolina
Lone Star Bleeding Disorders Foundation
Louisiana Hemophilia Foundation
Midwest Hemophilia Alliance
New England Hemophilia Association
New York City Hemophilia Chapter
Rocky Mountain Hemophilia & Bleeding Disorders Association
Texas Central Hemophilia
United Hemophilia Foundation
Utah Hemophilia Foundation
Virginia Hemophilia Foundation
Western Pennsylvania Chapter of the National Hemophilia Foundation
Wisconsin Bleeding Disorders Network

Contact Information:

*Hemophilia Federation of America
Sonji Wilkes, Senior Director of Policy, Advocacy & Government Education
Mobile: 303-887-2600
s.wilkes@hemophiliafed.org*

###

CC:

The Honorable Richard Neal, Chairman
United States House of Representatives Committee on Ways & Means

The Honorable Kevin Brady, Ranking Member
United States House of Representatives Committee on Ways & Means

The Honorable Chuck Grassley, Chairman United States Senate Committee on Finance

The Honorable Ron Wyden, Ranking Member United States Senate Committee on Finance

The Honorable Nita Lowey, Chairwoman
United States House of Representatives Committee on Appropriations

The Honorable Kay Granger, Ranking Member
United States House of Representatives Committee on Appropriations

The Honorable Richard Shelby, Chair
United States Senate Committee on Appropriations

The Honorable Patrick Leahy, Vice Chairman
United States Senate Committee on Appropriations