



**NATIONAL HEMOPHILIA FOUNDATION**  
*for all bleeding disorders*

September 24, 2019

Dear Chapter Leaders:

In the weeks following the distribution of a letter authored by the Chapter Services Organization (CSO) dated August 13, 2019, the National Hemophilia Foundation and Hemophilia Federation of America (NHF and HFA, respectively), have been working together to understand more about the statements and requests that were included in the letter stemming from the August 9<sup>th</sup> CSO meeting in St. Louis.

Our organization's highest priority remains our continued commitment to our member organizations and the individuals and families we are all privileged to serve. This has not and will not waver. Additionally, we are striving to be transparent throughout the process.

It is in this very commitment to transparency, in which this letter and report is being sent to chapters. NHF was asked by CSO leadership to respond to three main points prior to the meeting in St. Louis. Please note, it was a quick turnaround to respond in time for the St. Louis meeting, so not all data was included in the report. In addition, we know that not all NHF chapters were able to be present, so we want to share that information with all of you.

The following information was requested from NHF:

1. *What is NHF's ratio in 2018 for total revenue of industry vs. non-industry funding?*
2. *List all the services/programs NHF provided to member orgs/chapters in 2018?*
3. *How much did NHF give back in dollars to chapters in 2018 through programs, support, grants, board retreats, etc? Do not include any emergency assistance to community members.*
  - a. *If possible, please break this down by merged vs. non-merged chapters.*

We look forward to seeing you next week in Anaheim at the NHF Bleeding Disorders Conference. There will be ample opportunity to discuss the issues laid out in the CSO letter with both NHF staff and board members. Following BDC, NHF will work to send out our response specifically addressing each of your concerns. In the meantime, please know that we have been continuing to meet on a regular basis with HFA and are working together to define opportunities to collaborate, but also to find a way to better communicate those collaborations.

Thank you for your continued leadership in the community. We look forward to seeing you in Anaheim.

Sincerely,

NHF Board and Senior Leadership Team

Cc: HFA Leadership