April 17th, 2020

Dear \*Legislator\*,

I wanted to reach out as your constituent to talk to you about those affected by Bleeding Disorders here in Nebraska. We had planned to visit your office this week, but due to health and safety concerns with COVID-19, we were unable to do so. I’m instead sending you this letter which includes a little about us, bleeding disorder fact and figures and a red tie to commemorate Bleeding Disorders Awareness Month with the Red Tie Campaign.

Governor Polis in the past has proclaimed March as Bleeding Disorder Awareness month here in the State of Colorado. Bleeding Disorder advocates, during this month, wear a red material around their necks (ties, leis, scarves) as the tie that binds us all together. We have included a red tie for you in honor of this month. Bleeding disorders, which share the inability to form a proper clot, are characterized by extended bleeding after injury, surgery, trauma or menstruation and can lead to significant morbidity and can be fatal if not treated effectively. We hope this awareness month will generate greater awareness and understanding of not only hemophilia, but all inheritable bleeding disorders, including von Willebrand disease- which alone impacts an estimated one percent of the US population.

**\*\* Take this paragraph to tell about yourself and your experiences with having a bleeding disorder\*\***

We want you to be aware of legislation that affects the bleeding disorder community and other rare disease groups here in Colorado. Ongoing and affordable access to health care, pharmaceutical needs and affordable care is of the utmost important to our community. The treatment for hemophilia for one year can cost upwards of $300,000 for prophylactic treatment, with prices skyrocketing with injury or surgery. We ask that you do all you can to ensure that all Nebraskans have access to affordable healthcare, expanded Medicaid and product choice for their needed medication. Access to safe, effective and affordable treatment is extremely important to our community, especially in times like these where there is so much uncertainty.

We ask you to support the needs of all rare diseases, especially genetic disorders like hemophilia and von Willebrand disease, where there is no cure. We appreciate you taking the time to read our story and let us share with you about bleeding disorders. We would love if you could take a picture in the Red Tie and post it on your social media tagging the Colorado Chapter of the National Hemophilia and using the hashtag #redtiecampaign. It would mean a lot to us and let us know you have heard our message. We look forward to visiting you at the Capitol in 2021 as we continue to advocate for the Colorado Bleeding Disorder Community.

Sincerely,

Name and Address