



STATE OF HAWAII
DEPARTMENT OF HEALTH
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LATE

Testimony in SUPPORT of H.C.R. 16

DESIGNATING MARCH 2019 AS BLEEDING DISORDERS AWARENESS MONTH

REPRESENTATIVE JOHN M. MIZUNO, CHAIR
HOUSE COMMITTEE ON HEALTH

Hearing Date: March 21, 2019

Room Number: 329

1 **Fiscal Implications:** None.

2 **Department Testimony:** The Department of Health (DOH) supports House Concurrent
3 Resolution (H.C.R.) 16 designating March 2019 as Bleeding Disorders Awareness Month where
4 the DOH, the Department of Education (DOE), and the U.S. Department of Health and Human
5 Services are encouraged to spread awareness of common bleeding disorders, like hemophilia and
6 von Willebrand disease (VWD), and explain that proper treatment and support leads to healthy
7 and ordinary lifestyles.

8 According to the Centers for Disease Control and Prevention (CDC), hemophilia
9 primarily affects males, occurring in about 1 in every 5,000 male births. The CDC estimates that
10 20,000 people of all races and ethnicities in the U.S. are living with hemophilia. VWD is the
11 most common bleeding disorder, affecting up to 1% of the population.¹ While VWD affects
12 males and females equally, women are more likely to experience symptoms because of increased
13 bleeding related to menstruation, pregnancy, and childbirth.

14 The DOH does not currently address bleeding disorders through its existing programs,
15 but is willing to collaborate with the DOE and community partners such as the National
16 Hemophilia Foundation Hawaii Chapter, and the Kapiolani Hemophilia and Thrombosis
17 Treatment Center on increasing awareness of the disorders, as well as how proper treatment can
18 improve the quality of life for those with the conditions.

¹ Centers for Disease Control and Prevention. <https://www.cdc.gov/ncbddd/hemophilia/data.html>

- 1 The DOH supports H.C.R. 16 to designate March 2019 as Bleeding Disorders Awareness
- 2 Month in the State of Hawaii.

- 3 Thank you for the opportunity to provide testimony.

HCR-16

Submitted on: 3/18/2019 4:23:12 PM

Testimony for HLT on 3/21/2019 8:30:00 AM

Submitted By	Organization	Testifier Position	Present at Hearing
Donald "Douglas" Ziggy"	National Hemophilia Foundation - Hawai'i Chapter	Support	Yes

Comments:

To: Chair Mizuno and committee members of the House Committee **on Health & Human Services**

Subject: House Concurrent Resolution 16 – Designating March 2019 As Bleeding Disorders Awareness Month

March 18, 2019

Mahalo for the opportunity to testify on this bill. My name is Ziggy, and I am testifying in strong support of H.C.R. 16. This awareness resolution will help my Hawaii Bleeding Disorder community in so many ways, helping to spread awareness about rare bleeding disorders to the public in return helping to educate them about the condition. Both so very impactful to the Hawai'i bleeding disorders community now and into the future when trying to provide that education at schools, primary care physicians and even legislators like yourselves. Often the ones discussing and making "decisions", legislative or otherwise that could impact our health.

Thank you again for the opportunity to testify in strong support on HCR16, this matter of great importance to families across the state.

Name: Donald "Ziggy" Douglas

Contact Information: Executive Director, Hawaii Chapter of the National Hemophilia Foundation, 808-782-5506 / DDouglas@Hemophilia.org

Mahalo nui loa!

HCR-16

Submitted on: 3/20/2019 10:17:05 AM

Testimony for HLT on 3/21/2019 8:30:00 AM

Submitted By	Organization	Testifier Position	Present at Hearing
Lauren A Holomalia	Hawaii Chapter of NHF	Support	No

Comments:

As a mother, caretaker, and carrier of Hemophilia, I strongly support designating March as bleeding disorders awareness month. Hemophilia is a rare bleeding disorder that is both genetic and can begin as a spontaneous mutation, meaning anyone could be affected by it. Although we are a small community, we are mighty and love to share our mana'o and spread awareness of this disorder whenever possible. The Hawaii Chapter of NHF has truly been a god sent for my 'ohana and I. Hemophilia can affect individuals by spontaneous bleeds in joints, the brain, soft tissue, and exacerbate trauma to the body. Without the support of our local HTC and the Hawaii Chapter of NHF, my ohana and I would not be able to cope with the effects of this disorder. Through spreading awareness of this rare disorder, of chapter would be able to better support these families in need of assistance both financially and emotionally. With your help, we could further promote education within our Hawai'i community. Mahalo!

HCR-16

Submitted on: 3/19/2019 11:35:29 AM

Testimony for HLT on 3/21/2019 8:30:00 AM

Submitted By	Organization	Testifier Position	Present at Hearing
michael pieklo	Individual	Support	Yes

Comments:

Please support this ! Those of us and family members with Bleeding disorders are counting on you.

LATE

HCR-16

Submitted on: 3/20/2019 10:04:14 PM

Testimony for HLT on 3/21/2019 8:30:00 AM

Submitted By	Organization	Testifier Position	Present at Hearing
Ashley McElheny Pieklo	Individual	Support	No

Comments:

To: Chair Mizuno and committee members of the House Committee **on Health & Human Services**,

Subject: House Resolution 135 – Designating March 2018 As Bleeding Disorders Awareness Month

March 21, 2019

Mahalo for the opportunity to testify on this bill. My name is Ashley Pieklo, and I am testifying in strong support of H.R. 17 and H.C.R. 16.

This awareness resolution will help my Hawaii Bleeding Disorder community by raising awareness about the issues that people with bleeding disorders face and the needs of our community in Hawaii.

Thank you again for the opportunity to testify in strong support on this matter of great importance for families across the state.

Ashley Pieklo

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Mahalo!