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HR-45 (2021-2022)





REVISED JUNE 17, 2021

CALIFORNIA LEGISLATURE— 2021–2022 REGULAR SESSION

HOUSE RESOLUTION

NO. 45

Introduced by Assembly Member Levine

(Coauthors: Assembly Members Aguiar-Curry, Arambula, Bauer-Kahan, Bennett, Berman, Bigelow, Bloom, Boerner Horvath, Bryan, Burke, Calderon, Carrillo, Cervantes, Chau, Chen, Chiu, Choi, Cooley, Cooper, Cunningham, Megan Dahle, Daly, Davies, Flora, Fong, Frazier, Friedman, Gabriel, Gallagher, Cristina Garcia, Eduardo Garcia, Gipson, Grayson, Holden, Irwin, Jones-Sawyer, Kalra, Kiley, Lackey, Lee, Low, Maienschein, Mathis, Mayes, McCarty, Medina, Mullin, Muratsuchi, Nazarian, Nguyen, O'Donnell, Patterson, Petrie-Norris, Quirk-Silva, Rendon, Reyes, Luz Rivas, Robert Rivas, Rodriguez, Blanca Rubio, Salas, Santiago, Smith, Stone, Ting, Villapudua, Voepel, Waldron, Ward, Akilah Weber, and Wicks)

May 12, 2021

Relative to X-Linked Hypophosphatemia awareness.

LEGISLATIVE COUNSEL'S DIGEST

HR 45, as introduced, Levine.

WHEREAS, X-Linked Hypophosphatemia (XLH) is a whole-body, whole-life rare genetic disorder that affects the person from birth through childhood, adulthood, and advanced age, affecting the patient's muscular, skeletal, auditory, and nervous systems; and

WHEREAS, XLH affects about one in 20,000 newborns, according to the National Institutes of Health; and

WHEREAS, The effects of the disease cause serious and debilitation symptoms that have a major impact on the lives of those people who suffer from XLH and their families; and

WHEREAS, Patients affected by XLH and their families often encounter a variety of problems outside of the illness itself, such as difficulty in obtaining accurate and timely diagnoses, finding effective treatment options, and being able to afford the appropriate treatment; and

WHEREAS, XLH is not a curable disease; however, dedicated researchers around the world continue their efforts to understand how genetic mutations work with the hope that a cure will be developed one day; and

WHEREAS, Educational programs must be public and constant so that new parents and health providers can be exposed to the most up-to-date information; and

WHEREAS, The XLH Network, Inc., (www.xlhnetwork.org) is a nonprofit organization in support of caregivers and patients affected by XLH; now, therefore, be it

Resolved by the Assembly of the State of California, That the Assembly hereby proclaims June 23, 2021, as X-Linked Hypophosphatemia Awareness Day and June 2021 as XLH Awareness Month in California; and be it further

Resolved, That the Chief Clerk of the Assembly transmit copies of this resolution to the author for appropriate distribution.

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