

## THE UNITED STATES VIRGIN ISLANDS OFFICE OF THE GOVERNOR GOVERNMENT HOUSE Charlotte Amalie, V.I. 00802 340-774-0001

## RETT SYNDROME AWARENESS MONTH

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## BY THE GOVERNOR OF THE VIRGIN ISLANDS OF THE UNITED STATES

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## A PROCLAMATION

WHEREAS, Rett Syndrome is not well-known to many residents of the Territory or the country; therefore, there is a need for public awareness of this disorder; and

WHEREAS, Rett syndrome is a rare postnatal genetic neurological disorder that occurs almost exclusively in females, and rarely in males; and

WHEREAS, every 2 hours a girl is born with Rett syndrome, and its symptoms usually do not appear until the child reaches 6 to 18 months of age; and

WHEREAS, A regression period occurs where acquired motor skills are lost, leading to lifelong impairments including loss of speech, seizures, scoliosis, and irregular breathing patterns; and

WHEREAS, more than half of those diagnosed with Rett syndrome require maximum assistance with daily living activities; and

WHEREAS, the disorder is not degenerative and biomedical research suggests that neurological symptoms may be reversed even after decades of severe symptoms; and

WHEREAS, because of the discovery of the gene that causes Rett syndrome in 1999, as well as laboratory research in 2007 proving the theory of reversibility of the disease found, the discovery of breakthrough testing in vitro models in 2010, and the present launch of six disease-modifying human clinical trials; now is a historic moment in time to continue to fund truly life-changing research surrounding Rett syndrome; and

WHEREAS, it is necessary that we bring awareness to the disorder and its possible cure to those in the Territory of the United States Virgin Islands, and to join together with other states, cities, and counties who have made proclamations and resolutions for a Rett syndrome awareness month; and

WHEREAS, the International Rett Syndrome Foundation vis the world's largest private source of funds for Rett syndrome research addressing the full spectrum of this developmental disorder This organization brings awareness of the disorder and advocates for those affected, and works to improve the

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quality of life for patients and their families; and

WHEREAS, it is critical to fund the researchers who are dedicated to finding a cure for Rett syndrome, in order to promote a brighter future for those who suffer from the disease and until there is a world without Rett syndrome; and

WHEREAS, proclaiming a month of awareness for this disorder will help promote further awareness and funding for the treatment of Rett Syndrome to the medical community, therapists, teachers, caregivers, and the general public.

NOW, THEREFORE, I, Albert Bryan, Jr., Governor of the Virgin Islands of the United States, by virtue of the authority vested in me by the Revised Organic Act of the Virgin Islands, as amended, do hereby proclaim the month of October 2022 as "Rett Syndrome Awareness Month" in the Virgin Islands. I call upon all residents of the territory to become aware of and advocate for treatment, as well as continued medical research for a cure for all who suffer from the disease in our community and to work towards the elimination of Rett Syndrome.

IN WITNESS WHEREOF, I have hereunto set my hand and caused the Seal of the Government of the Virgin Islands of the United States to be affixed at Charlotte Amalie, St. Thomas, Virgin Islands, this 3<sup>rd</sup> day of October, A. D. 2022.

Albert Bryan, Jr. Governor

Attest:

Dorna Fred-Gregory
Acting Lieutenant Governor