

## **Proclamation**

## World PVNH Disorder Awareness Day August 7<sup>th</sup>, 2022

WHEREAS August 7th has been declared World PVNH Disorder Awareness Day, as created in Vancouver, BC in 2012 by PVNH Support & Awareness founder, Yolaine Dupont, and recognized by PVNH experts in nine countries including Canada; and

WHEREAS PVNH (periventricular nodular heterotopia) is a rare neuronal migration disorder that affects babies, children and adults alike around the world; and

WHEREAS PVNH can be associated with a spectrum of clinical manifestations from mild to debilitating—including seizures in up to 90% PVNH-affected individuals and motor, cognitive and developmental delays, often involving issues with multiple organs—and may be fatal if its symptoms are left unrecognized and untreated, and

WHEREAS HRM is proud to support PVNH Support & Awareness, a Vancouver-based international patient organization that offers support to 750+ individuals and families affected by PVNH and other neuronal heterotopia disorders in Canada and in 37 other countries worldwide; and

WHEREAS PVNH is not known to most medical professionals, and

WHEREAS Increased awareness, education and research are needed to find more effective treatments and therapies for side effects and, ultimately, a cure:

THEREFORE, be it resolved that I, Mayor Mike Savage, on behalf of Halifax Regional Council, do hereby proclaim, August 7th, 2022 as "PVNH Disorder Awareness Day" in the Halifax Regional Municipality.

Dated at Halifax, Nova Scotia This 7th day of August 2022

> Mike Savage Mayor