

Reps. Leonard, Allor, Brinks, Canfield, Chirkun, Clemente, Cochran, Crawford, Greig, Howrylak, Leutheuser, Love, Marino, Moss, Sneller and Wittenberg offered the following resolution:

House Resolution No. 380.

A resolution to declare September 2018 as Leukodystrophy Awareness Month in the state of Michigan.

Whereas, Leukodystrophy, sometimes referred to as white matter disease, makes up a group of rare genetic disorders that affect the central nervous system by disrupting the growth or maintenance of the myelin sheath, which insulates nerve cells in the brain; and

Whereas, Myelin, sometimes referred to as “white matter” because of its white, fatty appearance, protects and insulates the axons and consists of a protective sheath of many different molecules that include both lipids (fatty molecules) and proteins. It functions in a manner very similar to that of the protective insulation surrounding an electric wire; that is, being necessary for the rapid transmission of electrical signals between neurons. Myelin does so by containing the electrical molecules within the axons so that they are all properly transmitted to the next neuron and with a proper myelin sheath, neurons can transmit signals at speeds up to 60 meters per second; and

Whereas, Leukodystrophy damages this myelin sheath, causing a potential decrease by ten-fold or more based on this signal lost during transmission, decreasing the speed of signal transmission, and leading to significant disruption in the proper functioning of the nervous system; and

Whereas, The process of disruption in the proper functioning of the nervous system causes loss of normal function ultimately leading to severe multiple impairments and 100% dependence on caretakers; and

Whereas, Leukodystrophy is progressive, incurable, and fatal, and in many cases has taken the lives of children within a matter of months; and

Whereas, There are over 40 types of leukodystrophies, estimated to affect 1 in 7,000 people; and

Whereas, Institutions of stature continue researching many forms of leukodystrophy, looking for breakthroughs that may lead to a cure; and

Whereas, There is a lot that can be done to make life more positive for a person with leukodystrophy and their family, and having a network of support helps get through the hard times; and

Whereas, The great state of Michigan is filled with so many faithful, caring people and medical professionals that provide this network of support; now, therefore, be it

Resolved by the House of Representatives, That the members of this legislative body declare September 2018 as Leukodystrophy Awareness Month in the state of Michigan. We honor the patients who fight this disease each and every day, and the families who support them or have lost a loved one. During this month of September, we urge greater education and awareness of this rare genetic disorder.