A RESOLUTION

Designating the month of September 2020 as "Leukodystrophy Awareness Month" in Pennsylvania.

WHEREAS, Leukodystrophy is a rare and terminal disease presenting itself in multiple manifestations that attack the central nervous system, severely impacting physical abilities, mental capacity and quality of life; and

WHEREAS, The group of rare disorders known as leukodystrophies destroys the central nervous system by disrupting the growth and maintenance of myelin, a sheath that insulates nerve cells and destroys white matter in the brain; and

WHEREAS, Leukodystrophies are progressive, with symptoms that worsen throughout the life of the patient; and

WHEREAS, There are more than 50 identified leukodystrophies, yet nearly half of patients with leukodystrophy remain unclassified; and
WHEREAS, As research advances, scientists will continue to
discover and classify new variations in this family of diseases;
and
WHEREAS, Alone, each leukodystrophy may be considered rare,
but as a group these diseases affect approximately 1 in 7,000
individuals; and
WHEREAS, Infants born with leukodystrophy appear normal at
birth, yet, symptoms may appear during infancy or childhood; and
WHEREAS, Although there is no cure for leukodystrophy,
treatment may include medications, physical, occupational and
speech therapies and nutritional, educational and recreational
programs; and
WHEREAS, Additional treatment options such as bone marrow
transplantation are emerging due to continued research and
medical advances; and
WHEREAS, Organizations, including the United Leukodystrophy
Foundation, Hunter's Hope Foundation, The Myelin Project, the
MLD Foundation and the Adrenoleukodystrophy Foundation have
dedicated their work to public education, disease research and
patient treatment; and
WHEREAS, Act 148 of 2014 requires hospitals in this
Commonwealth to screen newborns for Krabbe disease, a
leukodystrophy; and
WHEREAS, X-linked adrenoleukodystrophy (X-ALD) was added to
the Federal Recommended Uniform Screening Panel in 2016; and
WHEREAS, Hospitals in this Commonwealth began screening all
newborns for X-ALD in April 2017; and
WHEREAS, It is imperative that parents learn about
leukodystrophy and understand the importance of screening and
early detection of Krabbe disease, X-ALD and other
leukodystrophies; therefore be it

RESOLVED, That the House of Representatives designate the
month of September 2020 as "Leukodystrophy Awareness Month" in
Pennsylvania; and be it further

RESOLVED, That the Commonwealth officially recognize the
importance of leukodystrophy awareness and encourage current and
future parents to educate themselves on these diseases and take
the necessary steps to ensure the health of their children.