

2017-K647

Assembly Resolution No. 647

BY: M. of A. Ra

MEMORIALIZING Governor Andrew M. Cuomo to proclaim
September 16, 2017, as Microvillus Inclusion Disease
Awareness Day in the State of New York

WHEREAS, Residents of the State of New York, as well as citizens of
the United States in general suffer from the little known and rare
genetic disorder Microvillus Inclusion Disease, also known as Davidson's
Disease; and

WHEREAS, This disorder causes the failing of an individual's
intestines and on the part of the victim and family causes great
distress; and

WHEREAS, Microvillus Inclusion Disease is incredibly rare, with only
a handful of cases seen not only throughout the United States but the
world as a whole; while cases are rare the suffering incurred by a
family who must live with this disorder is great; and

WHEREAS, At the present time, there is no cure for this genetically
caused disorder meaning that those affected and their families must do
what they can with limited resources to cope and live with this
disorder; and

WHEREAS, Today, there exists very little public awareness of

Microvillus Inclusion Disease globally; this serves to make support and funding difficult to come by for those suffering; and

WHEREAS, There are four cases throughout the United States, and in particular here in the State of New York where families must struggle with the day to day realities regarding this disorder; and

WHEREAS, There is one case of Microvillus Inclusion Disease in the State of New York which affects a young boy named Thomas Kevin Onorato from Nassau County; the Onorato family has been standing up for advocacy and awareness of Microvillus Inclusion Disease since Thomas was first diagnosed shortly after birth; and

WHEREAS, The Onorato family, along with several others have grouped together in forming the organization TKO, a non-profit foundation which works to bring families together who are affected by Microvillus Inclusion Disease, raise funds to help these families, and increase the awareness the general public has of the disease and its effects; and

WHEREAS, It is imperative that there be greater awareness of this serious health condition, and more must be done to increase activity at the local, State and National levels; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Andrew M. Cuomo to proclaim September 16, 2017, as Microvillus Inclusion Disease Awareness Day in the State of New York; and be it further

RESOLVED, That a copy of this Resolution, suitably engrossed, be transmitted to The Honorable Andrew M. Cuomo, Governor of the State of New York.