2015-K565

LEGISLATIVE RESOLUTION congratulating the New York City Hemophilia Chapter upon the occasion of the 10th Anniversary of its Hemophilia Walk

WHEREAS, It is the sense of this Legislative Body to recognize that the quality and character of life in the communities across New York State are enhanced by the concerned and dedicated efforts of organizations and individuals that generously contribute to the welfare of the community and its citizenry; and

WHEREAS, Attendant to such concern, and in full accord with its long-standing traditions, it is the sense of this Legislative Body to congratulate the New York City Hemophilia Chapter upon the occasion of the 10th Anniversary of its Hemophilia Walk in Riverside Park on the Upper West Side of Manhattan on May 31, 2015; and

WHEREAS, Hemophilia is a genetic bleeding disorder that prevents the blood from clotting normally and causes internal bleeding due to a missing or defective protein called the clotting factor; and

WHEREAS, Internal bleeding most often occurs in the muscles and joints, it can also occur in any organ including the brain, and may occur spontaneously, even without injury, resulting in pain, swelling and, if left untreated, permanent damage or even death; and

WHEREAS, Hemophilia is present in all demographic groups and affects approximately one in ten thousand people; it affects mostly males and there are some females with moderate or severe hemophilia and many more who are carriers and may also have mild hemophilia; and

WHEREAS, People with hemophilia face a lifelong condition that requires treatment through intravenous administration of the clotting factor derived from human blood and produced through pharmaceutical processes; and

WHEREAS, On the Upper West Side of Manhattan a particularly extraor-

dinary boy, Zak Stengel, who was born with severe Hemophilia A and must infuse himself with artificial clotting factor regularly, has made it his personal mission to educate and inform the public of hemophilia and the struggles associated with it; and

WHEREAS, With the loving support of his parents, Melissa Penn and Adam Stengel, and his siblings, Hope, Brody and Shao Shao Stengel, Zak has made television and other media statements and appearances, has testified about his disease, including before the United Nations, and has generally raised awareness of hemophilia; and

WHEREAS, Zak has received the Meritorious Service in Honor of Ryan White Award from the National Hemophilia Foundation as a result of his tireless advocacy; and

WHEREAS, Significant advances have been made in the diagnosis and treatment of hemophilia making it possible for Zak and others like him to live rich and active lives; however, there is no cure, and treatment can be extremely costly and beyond the means of many individuals; and

WHEREAS, For 10 consecutive years, the New York City Hemophilia Chapter has organized a Hemophilia Walk to raise money for education, advocacy and research in the pursuit of less invasive treatments and an eventual cure; and

WHEREAS, The Hemophilia Walk has steadily grown in participation, attendance and monies raised each year; and

WHEREAS, The New York City Hemophilia Walk now raises more than $250,000 each year; and

WHEREAS, The New York City Hemophilia Chapter has grown to where it can organize a broad variety of educational and community events throughout the year; and

WHEREAS, This particular event and others like it serve not only to raise funds, but to create a community of support for those individuals and their family and friends who are affected by the bleeding disorder; and

WHEREAS, The 2015 Walk has assumed the ambitious goal of attracting 2000 walkers, a testament to its increasing reach and popularity; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to congratulate the New York City Hemophilia Chapter upon the occasion of the 10th Anniversary of its Hemophilia Walk; and be it further

RESOLVED, That a copy of this Resolution, suitably engrossed, be transmitted to the New York City Hemophilia Chapter.