

PROCLAMATION

WHEREAS, there are nearly 7,000 diseases and conditions considered rare in the United States, according to the National Institutes of Health (NIH); and

WHEREAS, many rare diseases, such as Langerhans Cell Histiocytosis or Histiocytosis, are serious and debilitating conditions that have significant impact on the lives of those affected; and

WHEREAS, while more than 450 drugs and biologics have been approved for the treatment of rare diseases according to the Food and Drug Administration (FDA), millions of Americans still have rare diseases for which there is no approved treatment; and

WHEREAS, individuals and families affected by rare diseases often experience problems such as diagnosis delay, difficulty finding a medical expert, and lack of access to treatments or ancillary services; and

WHEREAS, while the public is familiar with some rare diseases such as “Lou Gehrig’s disease” and sympathetic to those affected, many patients and families affected by less widely known rare diseases such as Histiocytosis bear a large share of the burden of funding research and raising public awareness to support research treatments; and

WHEREAS, thousands of residents of Kentucky are among those affected by rare diseases since nearly one in 10 Americans have rare diseases; and

WHEREAS, the National Organization for Rare Disorders (NORD) is organizing a nationwide observance of Rare Disease Day on February 28, 2014; and

WHEREAS, thousands of patients and caregivers, medical professionals, researchers, companies developing orphan products to treat people with rare diseases, and others in the state of Kentucky will participate in that observance.

NOW, THEREFORE, I MARY H. BROWN, MAYOR OF THE CITY OF FORT THOMAS, CAMPBELL COUNTY, KENTUCKY, do hereby proclaim that February 28, 2014, be declared as:

“RARE DISEASE/HISTIOCYTOSIS DAY”

within the city of Fort Thomas in honor of Joseph S. Holt a local “Histiocytosis Warrior”, and hereby ask that local citizens will educate themselves and consider giving support to those affected by rare diseases.



Rare Disease Day

IN WITNESS WHEREOF, I have hereunto set my hand this 18th day of February, in the year of our Lord two thousand and fourteen.



Mary H. Brown, Mayor
City of Fort Thomas, Kentucky