



Text File

Introduced: 2/22/2021

Bill No: 2021-1236, **Version:** 1

Committee: City Council

Status: Adopted

WHEREAS, Rare Disease Day seeks to raise public awareness of rare diseases, mobilize public action, and urge elected officials and non-profit organizations to allocate research and funds to the many rare diseases that many patients live with; and,

WHEREAS, a rare disease is considered to be a disease that affects fewer than 200,000 people in the United States of America; and,

WHEREAS, an estimated 25,000,000 to 30,000,000 Americans are affected by a rare disease; and,

WHEREAS, more than 7,000 rare diseases exist, impacting more than 300,000,000 people worldwide, and at least 1 in 20 people - nearly six percent of the global population - will live their life with an incurable rare disease; and,

WHEREAS, due to limited scientific knowledge and study, diagnosis of rare diseases is flawed, often resulting in failed diagnosis for patients; and,

WHEREAS, due to the high rate of rare disease misdiagnosis many of those affected are not aware of their disease, bringing about negative impacts to their daily life; and,

WHEREAS, Rare Disease Day was first marked throughout Europe and Canada thanks to the work of the European Organisation for Rare Diseases (EURODIS) and the Canadian Organization for Rare Disorders on February 29, 2008; and,

WHEREAS, February 29, 2008 was the 25th Anniversary of the passing of the Orphan Drug Act in the United States of America, facilitating the development of drugs and treatments for rare diseases; and,

WHEREAS, February 28, 2009 marked the celebration of Rare Disease Day in the United States of America for the first time; and,

WHEREAS, the City of Pittsburgh recognizes the impact and importance that rare diseases have on our society and those living with and without a rare disease.

NOW, THEREFORE BE IT RESOLVED, that the Council of the City of Pittsburgh does hereby recognize **Rare Disease Day** on February 28, 2021.

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BE IT FURTHER RESOLVED, that the Council of the City of Pittsburgh does hereby call on the members of the Pennsylvania General Assembly to use state funds to combat the many rare diseases that our communities face.

BE IT FURTHER RESOLVED, that a copy of this Will of Council shall be sent to the Allegheny County delegation of the Pennsylvania State House and Senate, the chairs and minority chairs of the State House and Senate Public Health Committees, Governor Tom Wolf, and Pennsylvania Acting Secretary of Health Alison Beam.