



Legislation Details (With Text)

**File #:** Res 0211-2018      **Version:** \*      **Name:** Declaring the last day in February as Rare Disease Day in NYC.

**Type:** Resolution      **Status:** Laid Over in Committee

**In control:** Committee on Health

**On agenda:** 3/7/2018

**Enactment date:**      **Enactment #:**

**Title:** Resolution declaring the last day in February as Rare Disease Day in New York City.

**Sponsors:** Mathieu Eugene

**Indexes:**

**Attachments:** 1. Res. No. 211, 2. March 7, 2018 - Stated Meeting Agenda, 3. Committee Report 9/9/19, 4. Hearing Testimony 9/9/19, 5. Hearing Transcript 9/9/19

| Date     | Ver. | Action By           | Action                      | Result |
|----------|------|---------------------|-----------------------------|--------|
| 3/7/2018 | *    | City Council        | Introduced by Council       |        |
| 3/7/2018 | *    | City Council        | Referred to Comm by Council |        |
| 9/9/2019 | *    | Committee on Health | Hearing Held by Committee   |        |
| 9/9/2019 | *    | Committee on Health | Laid Over by Committee      |        |

Res. No. 211

Resolution declaring the last day in February as Rare Disease Day in New York City.

By Council Member Eugene

Whereas, According to Global Genes, a rare disease patient advocacy organization based in California, a disease is considered rare in the United States (U.S.) if it affects fewer than 200,000 persons; and

Whereas, There are approximately 7,000 different types of rare diseases and disorders; and

Whereas, Ten percent of the U.S. population, or 30 million people, are living with rare diseases and it is estimated that 350 million people worldwide suffer from rare diseases; and

Whereas, Eighty percent of rare diseases are genetic and approximately 50% of the people affected by rare diseases are children; and

Whereas, Rare diseases are often prevalent in pockets of ethnic minorities due to their genetic origin; and

Whereas, For example, sickle cell anemia is rare globally but an estimated 1 in 11 African Americans is a carrier and a person of 100% Ashkenazi Jewish descent has a 50% chance of carrying one of several rare

genetic diseases, according to the Genetic Disease Foundation; and

Whereas, According to an April 2013 Shire Rare Disease Impact Report, it takes an average of 7.6 years in the U.S. for a patient with a rare disease to receive a proper diagnosis; and

Whereas, A patient typically visits up to eight physicians and receives two to three misdiagnoses before the correct diagnosis is made; and

Whereas, The Shire report finds that rare disease patients in the U.S. face considerable financial hardship, including 55% of survey respondents stating that direct medical expenses were not covered by insurance, 37% had to borrow money from family and/or friends to pay for expenses, 34 percent sought help from charity or public assistance and 32% reported a negative impact on their credit score; and

Whereas, The economic strains and lengthy diagnosis process, as well as the lack of treatment options, available information and resources can take a major emotional toll on patients and their caregivers; and

Whereas, Patient and caregiver respondents in the Shire study reported depression (75% for patients, 72% for caregivers), anxiety and stress (86% for patients, 89% for caregivers), isolation from friends/family (65% for patients, 64% for caregivers), and worry based on future outlook of disease (90% for patients, 97% for caregivers); and

Whereas, The Orphan Drug Act of 1983 facilitates the development and commercialization of drugs to treat rare diseases by offering federal benefits to developers of medication designated as "orphan drugs"; and

Whereas, According to Global Genes, during the first 25 years of the Orphan Drug Act, only 326 new drugs were approved by the Food and Drug Administration and brought to market for all rare disease patients combined; and

Whereas, Global Genes also reports that approximately 50% of rare diseases do not have a dedicated foundation supporting or researching their rare disease; and

Whereas, Rare diseases with increased awareness also have an increased opportunity for research funding, as is the case with well-known but uncommon diseases such as Amyotrophic Lateral Sclerosis (ALS); and

Whereas, Rare Disease Day is an international awareness day on the last day in February organized by Eurordis, a non-governmental alliance of patient organizations and individuals focused on rare diseases in Europe, and the National Alliances, which are umbrella organizations who regroup several rare disease

organizations in a given country or region; and

Whereas, The number of countries participating in Rare Disease Day grows every year with 94 countries participating in 2017; and

Whereas, The objective of Rare Disease Day is to raise awareness among the general public, policy-makers, industry representatives, researchers, and health professionals about rare diseases and their impact on patients' lives; and

Whereas, The National Organization for Rare Disorders (NORD) partnered with Eurordis to sponsor and advocate for Rare Disease Day in the U.S., with education programs in schools and a "Handprints Across America" photo campaign to raise awareness; now, therefore, be it

Resolved, That the Council of the City of New York declares the last day in February as Rare Disease Day in New York City.

CP

LS 2626/Res 475/2014

LS 719

12/22/17