



# AGENDA REPORT

Mayor's Office

<b>DATE:</b>	March 1, 2022
<b>TO:</b>	Members of the City Council
<b>FROM:</b>	Tom Butt, Mayor
<b>Subject:</b>	Rare Disease Day – February 28, 2022
<b>FINANCIAL IMPACT:</b>	N/A
<b>PREVIOUS COUNCIL ACTION:</b>	N/A
<b>STATEMENT OF THE ISSUE:</b>	In 2008, the European Organisation for Rare Diseases recognized Rare Disease Day to raise awareness for rare diseases and improve access to treatment and medical representation for individuals with rare diseases and their families.
<b>RECOMMENDED ACTION:</b>	PROCLAMATION declaring February 28, 2022 as Rare Disease Day in the City of Richmond – Mayor's Office (Mayor Tom Butt 510-620-6503).

## DISCUSSION:

According to the National Institutes of Health, there are nearly 7,000 rare diseases and conditions that affect almost 30 million Americans, many of which are serious and debilitating conditions that have a significant impact on the lives of those affected.

According to the Food and Drug Administration, while more than 450 drugs and biologics have been approved for the treatment of rare diseases, millions of Americans still have rare diseases for which there is no approved treatment.

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. 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 bear a large share of the burden of funding research and raising public awareness to support the search for treatments.

To learn more, you can visit the website for the National Organization for Rare Disorders ([www.rarediseases.org](http://www.rarediseases.org)), a patient advocacy organization that is dedicated to individuals with rare diseases and the organizations that serve them and is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

**DOCUMENTS ATTACHED:**

Attachment 1 – Proclamation declaring February 28, 2022 as Rare Disease Day in the City of Richmond