

**MEMORANDUM**  
OFFICE OF THE  
**BOARD OF SUPERVISORS**  
COUNTY OF PLACER

**TO:** Honorable Board of Supervisors

**FROM :** Jennifer Montgomery, Supervisor District 5

**DATE:** February 25, 2014

**SUBJECT:** Approve and present a Proclamation proclaiming February 28, 2014 as Rare Disease Day in Placer County.

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**ACTION REQUESTED**

Approve and present a Proclamation proclaiming February 28, 2014 as Rare Disease Day in Placer County.

**BACKGROUND**

On February 28, 2014, the National Institutes of Health (NIH) will celebrate the seventh annual Rare Disease Day. Rare Disease Day was established to raise awareness with the public about rare diseases, the challenges encountered by those affected, the importance of research to develop diagnostics and treatments, and the impact of these diseases on patients' lives. The focus of Rare Disease Day is aligned with the Office of Rare Disease Research's (ORDR) philosophy that researchers need to work closely with patients and patient advocacy groups to maximize chances for success. This philosophy has been put into practice in the NIH's very successful Rare Diseases Clinical Research Network.

There are about 7,000 rare diseases identified in the United States. An estimated 80 percent of rare diseases are genetic in origin and approximately half of all rare diseases affect children. Rare diseases can be chronic, progressive, debilitating, disabling, severe and life-threatening. Information is often scarce and research is usually insufficient. People affected face challenges such as delays in obtaining a diagnosis, misdiagnosis, psychological burden and lack of support services for the patient and family. The goals remain for rare disease patients to obtain the highest attainable standard of health and to be provided the resources required to overcome common obstacles in their lives.

By highlighting these issues, the NIH Office of Rare Diseases Research hopes to:

- Raise awareness of rare diseases
- Strengthen the voice of patients and patient advocacy groups
- Give hope and information to patients
- Bring stakeholders closer together
- Coordinate policy actions within the United States and with other countries
- Inspire continued growth of the awareness of rare diseases
- Emphasize rare disease research and the search for new therapeutics
- Get equality in access to care and treatment

In support of the National Institutes of Health's Office of Rare Diseases Research in their goal for rare disease patients to obtain the highest attainable standard of health, the Board is requested to proclaim February 28, 2014 as Rare Disease Day in Placer County,

**FISCAL IMPACT**

None.

**IN THE MATTER OF A PROCLAMATION DECLARING  
FEBRUARY 28, 2014, AS "RARE DISEASE DAY"  
IN PLACER COUNTY.**

**WHEREAS:** Rare Disease Day was established by the National Institutes of Health to raise public awareness about rare diseases, the unique challenges encountered by people who are affected by them, and the importance of research to develop and improve diagnostics tools and treatments; and

**WHEREAS:** The focus of Rare Disease Day 2014 is to encourage researchers to work closely with patients and patient advocacy groups to maximize chances for success; and

**WHEREAS:** There are about 7,000 rare diseases identified in the United States, about 80 percent of rare diseases are genetic in origin, and it is estimated that about half of all rare diseases affect children; and

**WHEREAS:** Although rare diseases can be chronic, progressive, debilitating, disabling, severe and life-threatening, information about them is often scarce and research is usually insufficient; and

**WHEREAS:** People affected by rare diseases face challenges such as delays in obtaining a diagnosis, misdiagnosis, unique psychological challenges and lack of support services for the patient and family; and

**WHEREAS:** By highlighting these issues, the National Institutes of Health (NIH) Office of Rare Diseases Research will:

- Raise awareness of rare diseases
- Strengthen the voice of patients and patient advocacy groups
- Give hope and information to patients
- Bring stakeholders closer together
- Coordinate policy actions within the United States and with other countries
- Inspire continued growth of the awareness of rare diseases
- Emphasize rare disease research and the search for new therapeutics
- Get equality in access to care and treatment

**NOW, THEREFORE, BE IT PROCLAIMED THAT** that the Placer County Board of Supervisors proclaims February 28, 2014 as Rare Disease Day in support of the National Institutes of Health's Office of Rare Diseases Research in their goal for rare disease patients to obtain the highest attainable standard of health.

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Jack Duran, Supervisor, District 1  
Chairperson 2014

Robert M. Weygandt, Supervisor District 2  
Jim Holmes, Supervisor District 3  
Kirk Uhler, Supervisor District 4  
Jennifer Montgomery, Supervisor District 5