



DEPARTAMENTO DE

SALUD

GOBIERNO DE PUERTO RICO

PUBLIC NOTICE

TO ADOPT THE REGULATION OF THE OFFICE OF LIAISON FOR SUPPORT AND REGISTRY OF RARE DISEASES

By virtue of the powers and faculties granted by Act No. 81 of March 14, 1912, as amended, as well as Act No. 38-2017, as amended, the Secretary of Health intends to adopt the "Regulations of the Liaison Office for the Support and Registration of Rare Diseases". The purpose is to effectively implement Act No. 9-2025, which mandates the establishment of the "Liaison Office for the Support and Registration of Rare Diseases". This office will be part of the Department of Health, with the purpose of compiling, maintaining and updating an official registry of people suffering from rare diseases on the island, facilitating access to accurate diagnoses and innovative treatments, and coordinating efforts with national and international entities that specialize in the research and management of these conditions. In addition, it will serve as a mechanism for communication and coordination among patients, their families, health care providers, research centers and government entities, thus promoting comprehensive and effective care for patients.

The proposed regulation is published on the Department of Health's website: www.salud.gov.pr. The general public is invited to submit their comments or recommendations within thirty (30) days from the date of publication of this notice to the following address: a.ruiz@salud.pr.gov, or by regular mail addressed to the Department of Health, Legal Counseling Office, P. O. Box 70184, San Juan, P.R. 00936-8184. To submit your comments in person or request a copy of the proposed regulation, you should visit the Legal Counseling Office of the Department of Health, located in 1575 Ponce de León Avenue, State Road No. 8838, Km. 6.3 Rio Piedras Sector, Monacillos Ward, San Juan, Puerto Rico, Monday through Friday, from 8:00 a.m. to 4:30 p.m.

A virtual public hearing will be held on July 3, 2025, beginning at 9:30 a.m. Anyone interested in participating in the public hearing should send a message and provide their e-mail address to the following address: a.ruiz@salud.pr.gov and will receive an invitation with instructions on how to connect to the virtual public hearing.

In San Juan, Puerto Rico, on June 19, 2025.

VÍCTOR M. RAMOS OTERO, MD, MBA
SECRETARY OF HEALTH