

## **Biography – Maria Isabel Bueso Barrera, age 24**

Maria Isabel Bueso Barrera, or Isabel, lives with Maroteaux-Lamy Syndrome, also known as Mucopolysaccharidosis Type 6 (MPS-VI), a rare disorder caused by a gene abnormality. She was invited to the United States at seven years old to participate in a clinical trial for the only treatment for MPS-VI. Without commercial availability of the now FDA-approved treatment, Isabel and her family have stayed in the U.S. for 16 years under the medical deferred action program to ensure she has access to weekly, day-long infusion treatment. Without the treatment she will die.

She is an advocate for the rare disease community and helped to establish a bill introduced by Assemblymember Marc Levine to establish February 28 as Rare Disease Day in California. She also testified in support of a bill to create the Rare Disease Advisory Council in California. She graduated Summa Cum Laude from California State University East Bay and was Director of the Associated Students for the Concord Campus. She now works as an advocate for people with rare diseases and has visited the California State Capitol in Sacramento and the U.S. Capitol in Washington DC for several years in that capacity. This summer, she served as an intern at California Assemblymember Rob Bonta's District Office in Oakland, CA.