



NEW YORK STATE SENATOR

Andrew J. Lanza

Meghan Ortega

ANDREW J. LANZA May 11, 2016

| ISSUE: **2016 WOMEN OF DISTINCTION**



Women of
DISTINCTION
HONORING WOMEN IN NEW YORK

Meghan Ortega

Meghan Ortega, only 12 years old, has been in and out of the hospital since birth, battling countless medical challenges. She grew accustomed to going under the knife well before she reached third grade, and was finally diagnosed with the rare genetic disorder, Cowden Syndrome.

While Miss Ortega has endured many hardships, she has never had to face them alone. After learning that she has Cowden's disease, Miss Ortega's mother, Lori, was also tested and confirmed positive for the same disease. This explained multiple issues that they both

confronted. Since their diagnoses, mother and daughter have dedicated themselves to raising awareness about Cowden's and supporting others with rare diseases like the one they share.

Miss Ortega began her advocacy work at school, where she distributed information to her classmates and talked to them about her disease. She worked with a local jeweler to design a necklace, sold by the Global Genes Project, which serves as a visible symbol for those struggling with rare diseases. She also devised the slogan "Jeans for Rare Genes," which is now used as a fundraiser title. All while balancing school and weekly medical appointments, Miss Ortega has increased awareness about Cowden's Syndrome, promoted World Rare Disease Day, organized successful fundraisers and sent money to both the Global Genes Project and PTEN Foundation.

Despite all the physical and emotional burdens in her life, Miss Ortega's unwavering spirit has helped her earn excellent grades in school, a passion for reading and physical activity, and commitment to spreading awareness to others suffering from rare diseases.

Miss Ortega hopes to become a lawyer or geneticist so she can continue to advocate for people around the world who need help. She was recently named an "Inspirational Staten Islander" by the Staten Island Advance in recognition of her contributions to the borough.

In a world where people often get wrapped up in trivial frustrations, Miss Ortega remains an inspiration and a reminder that in the great scheme of things, people all around us are fighting very real battles.