Rare Disease Day
The **international** advocacy day to bring widespread recognition of rare diseases as a global health challenge.
A disease or disorder is defined as rare in the USA when it affects fewer than 200,000 Americans at any given time.
The Rare Disease Challenge

- lack of scientific knowledge and quality information;
- inequalities and difficulties in access to treatment and care;
- heavy social and financial burdens on patients;
- broad diversity of disorders and relatively common symptoms;
- initial misdiagnosis is common; and
- symptoms differ from disease to disease and patient to patient suffering the same disease.
Progress is being made every day!

- Better comprehensive approach to rare diseases;
- Development of appropriate public health policies;
- International cooperation in clinical and scientific research;
- Sharing knowledge of all rare diseases, not only the most “recurrent” ones; and
- Advances have led to new diagnostic and therapeutic procedures

HOWEVER, the road ahead is long....
OFFICIAL PARTNERS
2009 The United States joined Rare Disease Day

2013 Barack Obama sent a letter proclaiming his support of the day

2016 More than 80 events occurred in 35 states
RARE DISEASE DISPLAY
29 FEBRUARY 2016
A.I. DUPONT HOSPITAL FOR CHILDREN, WILMINGTON, USA
+13025733339
HOSTED BY DELAWARE HOSA

Delaware HOSA-Future Health Professionals and A.I. Hospital for Children are partnering to have HOSA members present rare disease displays. The HOSA members research a rare disease, connect with clinicians, researchers, and family members of children with a rare disease. Once the research is complete, HOSA members create a display with information about the rare disease and present on Rare Disease Day in the beautiful atrium of A.I. Hospital for Children.

HOSA members are also fundraising for rare disease research. Last year, more than $5000.00 was raised for Rare Disease Research. This event is a successful partnership with HOSA-Future Health Professionals, A.I Hospital for Children as well as the local, state, and larger national and international communities.
### Rare Disease Day Display

**Purpose:** To encourage Health Science students to improve their ability to present themselves, communicate rare disease information, and propose a cure/treatment or way to improve a quality of life issue.

**Description:** Teams consisting of two (2) competitors shall develop a visual display describing a specific rare disease as well as a proposed cure/treatment or way to improve a quality of life issue related to the rare disease. The display allows the students to express ideas through an artistic medium to highlight what they have learned about a particular rare disease through research, interactions with a patient and their family, and interactions with a researcher, clinician and/or other healthcare professional.

The students will also be judged on their ability to present themselves and communicate the rare disease information to others, as well as propose a cure/treatment or way to improve a quality of life issue.

The goal of this competitive event is to support policies and practices that:

1. facilitate research;
2. encourage development of innovative treatments;
3. advance awareness and understanding of rare diseases;
4. ensure patient access to care;
5. help break the isolation of the people living with rare diseases; and
6. provide opportunities for students to develop, practice, and refine their leadership and teamwork skills to achieve a seamless transition from education to a career.
The First State

• Interviews
  • Researchers
  • Family
  • Nurses
• Displays
• Presentations
• Rare Disease Day pins
• Fundraisers
Join the First State to bring widespread recognition!!