

National Rare Disease Day



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National Rare Disease Day is held annually on the 28th of February (29th in leap years-the rarest day on the calendar). This day was established to raise awareness and improve the lives of individuals living with a rare disease. To mark the day, patients, their families, caregivers, researchers, advocates, and many other stakeholders take part in a wide variety of activities. Rare Disease Day started in Europe in 2008, but has since spread all over the world. The National Organization for Rare Disorders (NORD) is the official U.S. partner for Rare Disease Day.

What exactly defines a rare disease? In the U.S., it is defined as a health condition that affects less than 200,000 people. Even though one rare disease may not affect many people, there are over 300 million people worldwide that suffer from one of the more of the 7,000 known rare diseases. (More than AIDS and cancer combined). Many of these diseases can be linked to genetics such as cystic fibrosis or muscular dystrophy and can be inherited or occur spontaneously.

Often times, someone suffering from a rare disease will face misdiagnosis, treatment inequity and isolation. The search for the diagnosis can be an extremely long process involving one or more specialists and much testing to identify the cause. On average, it can take 4 to 5 years to get an accurate diagnosis. And even after receiving the diagnosis, treatment isn't always available. Only about 5% of known rare diseases have an approved treatment. These approved treatments can be extremely expensive and hard to find for the patient. In 1983, The Orphan Drug Act was passed to provide incentives for the development of treatments for rare diseases by providing resources such as grant funding.

Meanwhile, the Complex Medical Help (CMH) Program, which operates through the Ohio Department of Health (ODH), provides assistance to individuals aged birth to 26 years with special health care needs that meet certain criteria. For more information on the CMH program, contact Angella Rosler at the Meigs County Health Department at (740)992-6626 or angella.rosler@meigs-health.com.

Rare diseases are an important public health concern. They can affect anyone of any age, race or gender. Raising awareness is the first step to supporting Rare Disease Day. Everyone who has an experience with a rare disease is highly encouraged to share their story to help promote and advocate for those living with these conditions.