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February 28, 2019

## Health Department Hopes to Increase Awareness of Rare Disease Day

Rare Disease Day is globally recognized on the last day of February each year. The main objective of Rare Disease Day is to raise awareness amongst the general public about rare diseases and their impact on patients' lives. The Board of County Commissioners in Lucas County passed a resolution to recognize February 28, 2019 as Rare Disease Day in Lucas County.

Rare diseases are present across the medical spectrum. Some are widely recognized by name, such as cystic fibrosis (CF). Others are less known, such as the skin condition epidermolysis bullosa (EB). Most forms of cancer are considered rare diseases.

In the U.S., any disease affecting fewer than 200,000 people is considered rare. This definition comes from the Orphan Drug Act of 1983. There are more than 7,000 rare diseases affecting 25-30 million Americans. Approximately one in ten Americans are suffering from rare diseases and more than half of them are children, equating to one person on your daily elevator ride.

Of the 7,000 known rare diseases, approximately 95 percent have no treatment. Many rare diseases and disorders are not even being studied by medical researchers. Awareness initiatives, like Rare Disease Day, are changing that.

Building awareness of rare diseases is so important because 1 in 20 people will live with a rare disease at some point in their life. Despite this, there is no cure for the majority of rare diseases and many go undiagnosed. Rare Disease Day improves knowledge amongst the general public of rare diseases while encouraging researchers and decision makers to address the needs of those living with rare diseases.

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