



Please Support the Creation of a National Emergency Treatment Database For Rare Disease Patients

Background: There are more than 7,000 rare disorders that affect more than 30 million Americans and their families – that’s about one in every 10 Americans. Of these 30 million, half are children. Rare or orphan diseases are defined as diseases affecting fewer than 200,000 people in the U.S. and include rare cancers, tropical or neglected diseases, genetic diseases and many pediatric diseases and cancers.

Many of these diseases are life threatening and have no emergency treatment protocols. For those diseases *with* emergency treatment options, emergency treatment protocols do not exist, resulting in delayed treatment and unnecessary deaths. Even if a patient has worked with their doctor to establish emergency treatment protocols, the current EMS protocols of many states do not address emergency treatment for rare disease patients or allow emergency medical response personnel to treat individuals with medical id with their diagnosis on it. Too many rare disease patients suffer unnecessarily from delayed medical care in emergency situations.

The science exists for many of these diseases to be treated in emergency scenarios; however, protocols may never be developed because of roadblocks in the development process, such as a lack shared rare disease patient information and a challenging EMS environment. Many EMS units operate independently by individual county, leaving patients unprotected when they travel across county or state lines into areas where their protocols might not be observed by that area’s EMS.

Solution: The proposed “Database” will prevent delayed treatment and unnecessary deaths in the treatment of rare disease patients in emergency situations and provide continuity of coverage for patients, even when they travel outside of their home area. A National Emergency Treatment Database for Rare Disease Patients will help raise awareness to the unique emergency treatment needs of the rare disease community- patients, physicians, scientists, and industry, and create opportunities to establish effective emergency treatment protocols.

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Database Design: The database would be cloud based, multi-firewalled, and could be accessed via a web browser, mobile device application, or desktop application specifically written for a Windows desktop OS platform (this would be used by doctors and other emergency medical providers).

The database would be encrypted with a patient's full record access requiring either two or three factor authentication. EMS could have a quick access to show limited information such as Emergency Treatment Protocols and medications to be able to provide emergency treatment in the field. Patients would identify themselves as registry members via medical bracelets, QR code stickers on their vehicles and drivers licenses, and local notification of EMS.