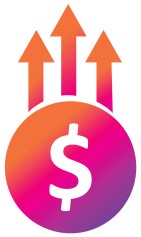
Newborn Screening

RARE READY COALITION

The Cost of Delayed Diagnosis is Measured in Lives and Dollars

Newborn screening uses a heel-prick blood sample to identify serious conditions early, when treatment is most effective. States are screening for **fewer than 1% of rare diseases**, with many states omitting conditions even though there is an FDA-approved treatment.



On average, a rare disease diagnosis takes more than six years and nearly 17 medical encounters after symptoms start, creating a significant economic burden—**exceeding $517,000 per patient**.[2]

More than 10,000 rare diseases exist, **affecting 1 in 10 Americans**. 80% of rare diseases are genetic, 70% begin in childhood, and 30% of affected children do not survive past age five.[1]

Early diagnosis saves lives—and saves healthcare dollars. Identifying diseases before symptoms appear enables timely treatment, prevents irreversible complications, and reduces costly care.

Come see us at booth 5125

[1] "Rare diseases: a global priority for equitable care." The Lancet, 2023. (Referenced by CDC Public Health Genomics.)

[2] "The Cost of Delayed Diagnosis in Rare Disease." EveryLife Foundation, 2023.

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