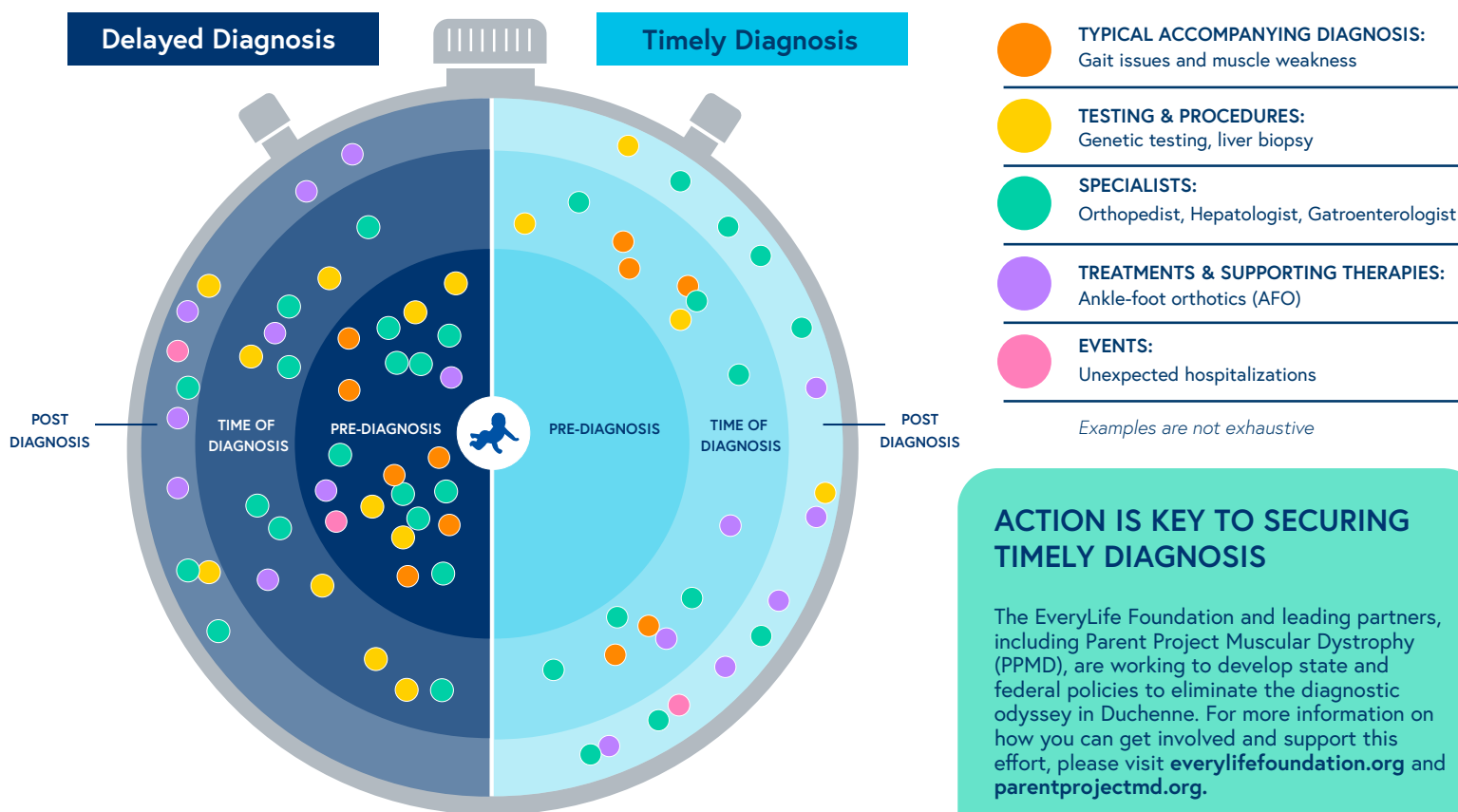


The Cost of Delayed Diagnosis in Rare Disease: *A Health Economic Study*

The Impact of Delayed Diagnosis in Duchenne

Navigating a rare disease diagnosis can require more than 6 years and 17 medical interventions, on average, after symptoms begin, including emergency room visits and out-of-state specialist appointments.¹ We took a detailed look into Duchenne muscular dystrophy, a rare neuromuscular condition, to illustrate the significant economic impact of this diagnostic odyssey.

Every Minute Matters



DELAYED DIAGNOSIS DRAMATICALLY INCREASES COSTS FOR FAMILIES*

\$211,229 Total medical cost and productivity loss per family

20 Lost days of work for caregivers each year

17 Out-of-state trips for medical care across the 7 communities studied

*Across the diagnostic odyssey

How Did We Collect These Data?

- Medicare and Commercial insurance claims data, including patients with Duchenne
- Results from The Rare Disease Financial and Social Impact Survey, completed by 1,409 community members

BENEFITS OF TIMELY DIAGNOSIS

Timely diagnosis, defined as before five years old for children with Duchenne^{2,3}, can improve health outcomes by:

- Providing earlier access to supportive therapies and treatment
- Delaying disease complications and physical disabilities
- Lowering costs for patients and families by reducing or eliminating costly and unnecessary services or procedures

Reference:

1. Yang G, Cintina I, Zhou M, et al. The National Economic Burden of Rare Disease Study. The EveryLife Foundation for Rare Diseases. https://everylifefoundation.org/wp-content/uploads/2021/02/The_National_Economic_Burden_of_Rare_Disease_Study_Summary_Report_February_2021.pdf. Published February 25, 2021. 2. Ciafaloni E, Fox D, Pandya S. Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet). J Pediatr. 2009;155(3):380-385. 3. Families Continue to Experience Delay in Getting a Diagnosis of Duchenne Muscular Dystrophy. National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention; 2023. <https://www.cdc.gov/ncbddd/musculardystrophy/features/delay-in-diagnosis-of-duchenne-muscular-dystrophy.html>

