Economic burden of rare disease reached nearly $1 trillion in the U.S. in 2019

ABOUT THE NATIONAL ECONOMIC BURDEN OF RARE DISEASE STUDY

This study, conducted by the Lewin Group on behalf of the EveryLifeFoundation for Rare Diseases, is the first of its kind, providing the most comprehensive assessment of the total economic burden of 379 rare diseases in a single year. This study identified direct medical costs, via an analysis of claims data, and indirect and non-medical and uncovered healthcare costs, via a survey of 1,399 members of the rare disease community.

$418 Billion

DIRECT MEDICAL COSTS

Includes inpatient hospital or outpatient care, physician visits, Rx medications, durable medical equipment.

$437 Billion

INDIRECT COSTS: PRODUCTIVITY LOSS

Includes forced retirement, absenteeism, presenteeism, and a reduction in community participation and volunteer service.

$111 Billion

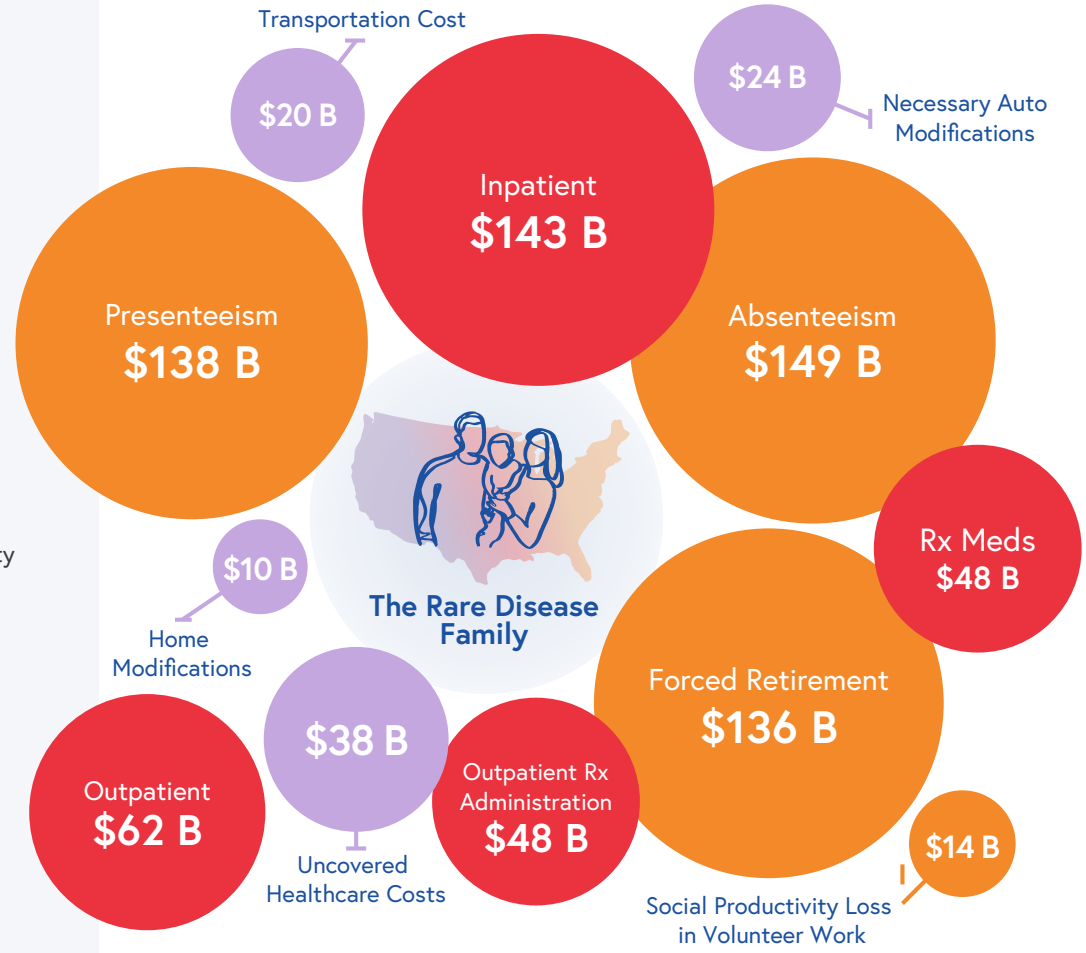
NON-MEDICAL & UNCOVERED HEALTHCARE COSTS

Includes paid daily care, necessary home and vehicle modifications, and transportation and education costs. Also includes healthcare services not covered by insurance: experimental treatments, medical foods, and more.

Total Economic Burden of Rare Disease in the U.S in 2019:

$966 Billion

LEADING COST COMPONENTS



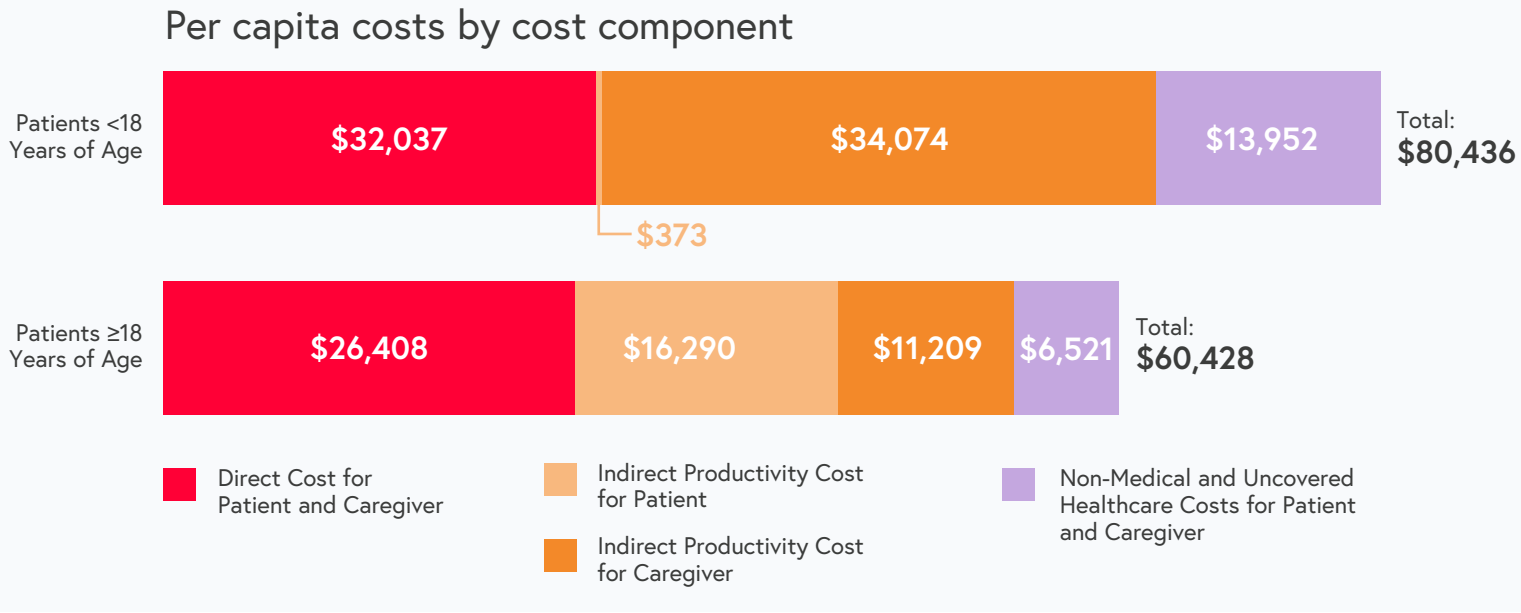
> *The National Economic Burden of Rare Disease Study is a defining moment in a decades-long effort to overcome the challenges of rare diseases. This new economic evidence can guide policy decisions with real and lasting benefits for families and society.* ***We must act on it.***

Mark Dant
Chair, Board of Directors,
The EveryLife Foundation for Rare Diseases
Father of a son with a rare disease

EVERYLIFE FOUNDATION FOR RARE DISEASES

The National Economic Burden *of* Rare Disease Study

What is the Impact on the Average Rare Disease Family?



> *The financial challenges are overwhelming and unrelenting. The search for a diagnosis or treatment requires navigating a complex medical system and battling with insurance companies – all while trying to hold down a job.*

Marissa Penrod
Founder, Team Joseph
Mother of a son with a rare disease

What Do the Study Findings Mean?

Within the rare disease community, it has been well understood that the costs of living with a rare disease, both economic and social, are immense. Yet, no one has previously examined the true cost at scale in the US. Determining the true economic cost of rare diseases equips the rare disease community with new tools with which to increase awareness of the public health crisis of rare disease, inform policy proposals, and improve the lives of patients and their families.

HOW CAN I GET INVOLVED?

Addressing the full range of needs codified by this study will require a collaborative effort. The scientific community, policy makers, healthcare providers, payers, employers, and others, all have a role to play to identify innovative new ways to improve the care and treatment of rare diseases.

CLICK HERE TO DOWNLOAD THE FULL SUMMARY REPORT

For more information on how you can get involved and support this effort, please visit everylifefoundation.org or contact us at info@everylifefoundation.org.