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

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

INDIRECT COSTS:
PRODUCTIVITY LOSS
Includes forced retirement, absenteeism, presenteeism, and a reduction in community participation and volunteer service.

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

About the National Economic Burden of Rare Disease Study
This study, conducted by the Lewin Group on behalf of the EveryLife Foundation 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.

Leading Cost Components

- Inpatient: $143 Billion
- Absenteeism: $149 Billion
- Presenteeism: $138 Billion
- Forced Retirement: $136 Billion
- Necessary Auto Modifications: $24 Billion
- Transportation Cost: $20 Billion
- Rx Meds: $48 Billion
- Uncovered Healthcare Costs: $48 Billion
- Home Modifications: $10 Billion
- Social Productivity Loss in Volunteer Work: $14 Billion
- Outpatient: $62 Billion
- Outpatient Rx Administration: $38 Billion
- Outpatient Rx: $48 Billion

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
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.

**What is the Impact on the Average Rare Disease Family?**

<table>
<thead>
<tr>
<th>Cost Component</th>
<th>Patients &lt;18 Years of Age</th>
<th>Patients ≥18 Years of Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct Cost for Patient and Caregiver</td>
<td>$32,037</td>
<td>$26,408</td>
</tr>
<tr>
<td>Indirect Productivity Cost for Patient</td>
<td>$34,074</td>
<td>$16,290</td>
</tr>
<tr>
<td>Indirect Productivity Cost for Caregiver</td>
<td>$13,952</td>
<td>$11,209</td>
</tr>
<tr>
<td>Non-Medical and Uncovered Healthcare Costs for Patient and Caregiver</td>
<td>$373</td>
<td>$6,521</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>$80,436</strong></td>
<td><strong>$60,428</strong></td>
</tr>
</tbody>
</table>

**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.