



# BURDEN OF RARE DISEASE

*a literature review*

## MEDICAL COSTS

**\$69,275**

The average cost **per hospital stay** for an individual with a rare disease is **\$69,275**.<sup>1</sup>

**\$28,913**

The average **annual medical cost** for an individual with a rare disease is **\$28,913 more** than an individual without a rare disease.<sup>2</sup>

**\$4,670**

Individuals with a rare disease typically pay **\$4,670** for **emergency room** visit charges.<sup>1</sup>

## FINANCIAL HARDSHIPS

Individuals with a rare disease and their caregivers may experience the following changes to their jobs:<sup>2</sup>

**Frequent absences from work**

**Unproductive days due to illness**

**Forced early retirement**

# FINDING A DIAGNOSIS

On average, rare disease patients wait **6.3 years** before receiving a **confirmed diagnosis**, and **are often misdiagnosed**.<sup>3</sup>

**6.3 years**

Finding a diagnosis may require **traveling far from home** and **visiting many medical specialists**.<sup>5</sup>



Many factors may complicate a diagnosis such as:<sup>4</sup>

Lack of knowledge of the rare disease

Misdiagnoses

Lack of available diagnostic tests

Lack of accessibility to medical specialists

Symptoms overlap with other diseases

# TREATMENT & MANAGEMENT



No treatment may be available<sup>5</sup>



Limited number of treatments are available for rare disease<sup>5</sup>



5% of rare diseases have FDA approved treatments<sup>4</sup>



Treatments may be expensive<sup>5</sup>



The average number of specialists that an individual with a rare disease sees is 17.<sup>3</sup>



Individuals with a rare disease tend to have longer hospital stays<sup>1</sup>

## OTHER BURDENS



Individuals with a rare disease may suffer from social stigmas that may not allow them to participate in everyday activities.<sup>5</sup>



Lack of data sharing regarding an individual's medical history, disease progression, treatment, interventions, and outcomes can lead to difficulties with advancing diagnostics and treatments.<sup>5</sup>

# REFERENCES

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