



Societal impact and economic burden of lipodystrophy in Bulgaria

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INTRODUCTION

Berardinelli-Seip congenital generalized lipodystrophy (CGL) is a rare disorder characterized by almost complete lipoatrophy, often leading to severe metabolic complications due to low leptin and elevated triglyceride levels. In Bulgaria, there are five confirmed CGL cases: three adult and two paediatric female patients.

OBJECTIVE

The objective of this analysis is to quantify the economic, social, and health burden of CGL in Bulgaria, focusing on direct medical costs, lost productivity, and years of life lost (YLL). The perspective of the analysis includes the payer National Health Insurance Fund (NHIF) in Bulgaria and society.

RESULTS: DIRECT COSTS

The direct medical costs for CGL in Bulgaria in 2024 total BGN 1.61 million for the pediatric patients, with 99,22% (BGN 1.59 million) of those costs being for leptin replacement therapy and 1,43% (BGN 22,985.48) for medical services and add-on drug therapy. The adults do not receive leptin replacement therapy and their contribution towards the direct costs are not significant.

RESULTS: INDIRECT COSTS

Of the five CGL patients in Bulgaria, three are projected to have no lifetime GDP contribution, resulting in an estimated loss of 5.87 million BGN due to inability to work. Additionally, two working patients will face an estimated 1.96 million BGN in lost GDP due to premature mortality, leading to a total economic impact of approximately 7.82 million BGN over the patients' lifetimes.

Direct costs: paediatric patients

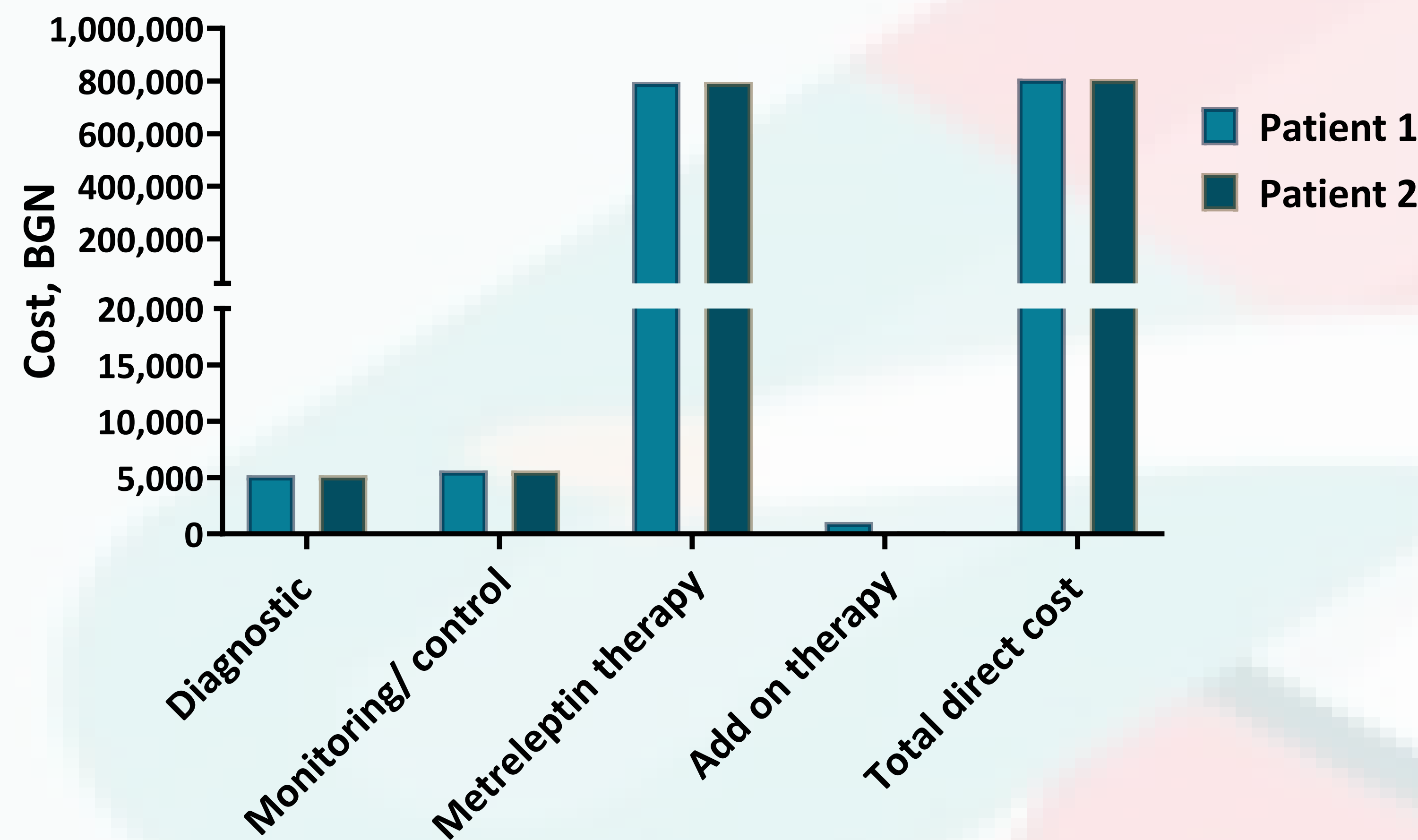


Figure 1. Direct costs of CGL in the two Bulgarian paediatric patients in 2024 presented by cost category.

Indirect costs by cause: adult patients

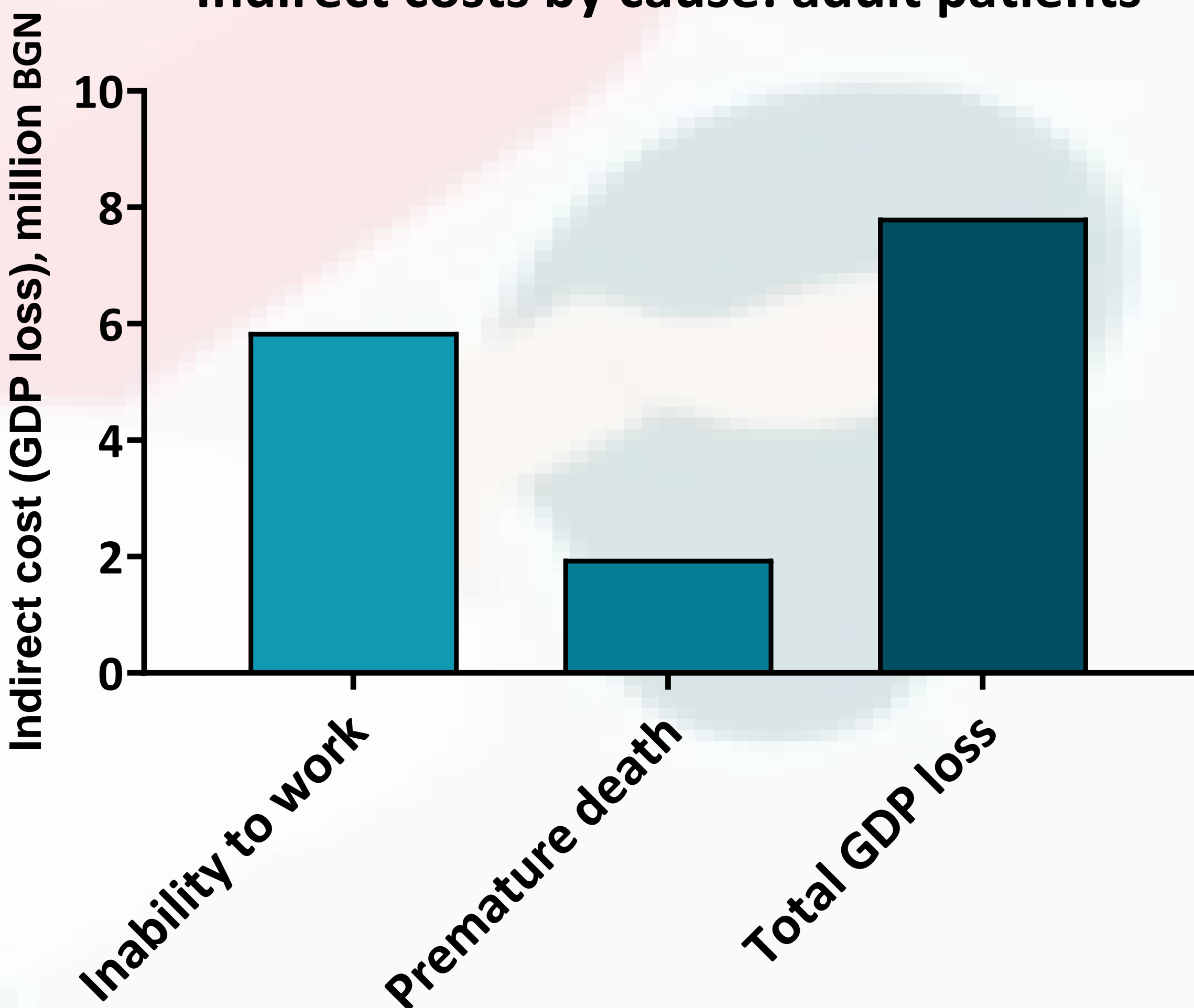


Figure 2. Indirect costs of CGL presented by cause of work impairment for all analysed patients (lifetime horizon).

RESULTS: YLL

As there is no available data on Disability-Adjusted Life Years (DALY) specifically for lipodystrophy patients, this analysis presents the available data on Years of Life Lost (YLL). Based on expert opinion, the life expectancy of patients with lipodystrophy is approximately 40 years. Given that the average life expectancy in Bulgaria in 2022 was 71.91 years, each patient with CGL is expected to lose approximately 31.91 YLL.

CONCLUSION

The analysis highlights the substantial economic and healthcare burden of CGL in Bulgaria. With high direct treatment costs for paediatric patients, and significant lifetime GDP losses from affected adult patients unable to work, the findings underscore the urgent need for targeted treatment strategies. Investing in therapies like leptin replacement could reduce long-term healthcare expenses and improve productivity outcomes. This information aids policymakers in understanding the economic implications of rare diseases like CGL and supports the development of comprehensive support systems to enhance patient outcomes and relieve economic strain.