News From The Employee Benefit Research Institute

Employee Benefit Research Institute Study Finds Cell and Gene Therapy Use Remains Rare but Rising Slowly in Employer Health Plans

New research uses claims data to examine utilization, spending and strategies employers are exploring to manage financial risk

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(Washington, D.C.) – The Employee Benefit Research Institute (EBRI) today released a new report, "Cell and Gene Therapies in Employment-Based Health Insurance: Financing the High-Cost, High-Impact Future," finding that use of cell and gene therapies in employer health plans remains rare — 9.2 per 100,000 in 2022 — but is rising gradually, and costs are concentrated among a small share of claimants.

Cell and gene therapies (CGT) are a rapidly advancing frontier in medicine, offering the potential to treat — and in some cases cure — serious conditions, such as sickle cell disease and hemophilia, by targeting diseases at the cellular or genetic level. While it can be transformative for patients, CGT is among the highest-cost treatments in health care. As approvals continue and the pipeline expands, employers and plan sponsors may face growing financial risk.

Using claims data, EBRI analyzed the prevalence of conditions targeted by cell and gene therapies, utilization patterns and spending among users, highlighting how costs can be concentrated among a small subset of high-cost claimants and what that may mean for plan financing and benefit design.

Key findings in the new research report include:

• **Rising Number of Approvals:** As of 2025, the U.S. Food and Drug Administration has approved 48 CGTs, with more in development. A growing number of these therapies are targeting conditions that are more common than traditional rare diseases. While utilization remains limited, the expanding pipeline suggests employers may need to prepare for broader financial exposure in coming years.

• **Modest Growth in Use:** Use of CGTs remains limited but has shown a gradual increase. In 2018, 7.9 per 100,000 enrollees received a CGT; by 2022, the rate rose to 9.2 per 100,000.

• **Small Share of Spending:** CGT users represent fewer than 0.1% of the enrollee population but account for approximately 0.5% of total spending. This includes both the cost of CGTs and spending on other health services. These proportions remained relatively stable between 2018 and 2022.

• **Impact on High-Cost Claimants:** Among enrollees in the top 1% of total health care spenders, just

0.58% used CGTs. However, these individuals accounted for 1.6% of spending within that top spending group. While the share is small, it signals that CGTs can meaningfully impact spending patterns among high-cost claimants.

“Cell and gene therapies remain uncommon in employment-based plans today, but the trajectory matters. Our analysis shows utilization rising gradually and spending concentrated among a small share of high-cost claimants — signals that employers, insurers, and policymakers should begin testing financing and payment models now to preserve access while managing risk as the CGT pipeline expands,” said Paul Fronstin, director, Health Benefits Research, EBRI.

Why it matters for employers and plan sponsors

The EBRI analysis notes that traditional cost-sharing tools (such as deductibles and out-of-pocket maximums) may have limited influence on utilization among the highest-cost claimants, including those receiving CGTs. Employer size also shapes risk management: Larger self-insured employers can spread risk more easily across a bigger covered population, while smaller employers may be more exposed and often rely on stop-loss insurance — an approach that can have limitations, including exclusions for known high-cost individuals. For smaller self-insured employers, even a single $1 million claim can represent a double-digit share of annual health spending.

To manage CGT-related financial exposure, employers and insurers are exploring approaches such as stop-loss insurance, carve-out programs, gene therapy reinsurance, value-based payment arrangements, performance-based contracts, amortization, and other risk-spreading mechanisms. The EBRI study also notes that many of these strategies are promising but remain largely unproven at scale for CGTs, making continued evaluation essential.

To review the new research report, visit https://www.ebri.org/publications/research-publications/issue-briefs/content/cell-and-gene-therapies-in-employment-based-health-insurance--financing-the-high-cost--high-impact-future.

The Employee Benefit Research Institute is a nonprofit, independent and unbiased research organization that provides the most authoritative and objective information about critical issues relating to employee benefit programs in the United States. The organization also coordinates activities for the Center for Research on Health Benefits Innovation, Financial Wellbeing Research Center and Retirement Security Research Center and produces a variety of leading industry surveys during the year. For more information, visit www.ebri.org.

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(MEDIA NOTE: To receive and review the complete research report, email Ron Dresner at dresner@ebri.org).