ACHP
ALLIANCE
OF COMMUNITY HEALTH PLANS

March 20, 2024

Chairman Ron Wyden
Senate Finance Committee
Washington, D.C. 20510

Ranking Member Mike Crapo
Senate Finance Committee
Washington, D.C. 20510

Chairman Bernie Sanders
Senate HELP Committee
Washington, D.C. 20510

Ranking Member Bill Cassidy
Senate HELP Committee
Washington, D.C. 20510

Chairman Jason Smith
House Ways and Means Committee
Washington, D.C. 20515

Ranking Member Richard Neal
House Ways and Means Committee
Washington, D.C. 20515

Chairwoman Cathy McMorris Rodgers
House Energy and Commerce Committee
Washington, D.C. 20515

Ranking Member Frank Pallone
House Energy and Commerce Committee
Washington, D.C. 20515

Dear Chairman Wyden, Ranking Member Crapo, Chairman Sanders, Ranking Member Cassidy, Chairman Smith, Ranking Member Neal, Chairwoman McMorris Rodgers and Ranking Member Pallone,

On behalf of the Alliance of Community Health Plans (ACHP), I write to urge your respective Committees to hold hearings this year examining the high-cost cell and gene therapies rapidly gaining FDA approval.

Cell and gene therapies are medical advancements intended to treat or cure genetic diseases, such as sickle cell disease, by transforming and curing the cells and genes themselves. Although these medical advancements provide immense promise for patients suffering from rare, life-threatening diseases, the price tags are exorbitant, threatening the long-term sustainability of the nation's health care system.

ACHP and its member companies are committed to providing high-quality, affordable coverage and care. ACHP is the only national organization promoting the unique payer-provider aligned model in health care, delivering coordinated, comprehensive coverage options. ACHP member companies collaborate with their clinical partners to deliver care to tens of millions of Americans in 40 states and D.C. Deeply rooted in their communities, ACHP members understand the value of an integrated system of care in which providers, payers and community leaders align to enhance access to services and improve health outcomes.

There is a rapidly growing need for federal policymakers to engage on the issue of cell and gene therapies, specifically how the country will balance the need for patient access with the soaring up-front prices of these therapies. In December 2023, the FDA approved Casgevy and Lyfgenia for the treatment of patients with sickle cell disease. At $2.2 and $3.1 million, respectively, and a possible patient population of 100,000 Americans, the potential cost could be more than $200 billion, not accounting for any associated care of this complex illness.

Therapies treating sickle cell could increase the nation's spending on prescription pharmaceuticals and therapeutics by nearly 50 percent. The health care system simply cannot afford this cost, especially when considering the full pipeline of other potentially life-changing therapies.

The pharmaceutical and banking industries are making vast investments in the development of cell and gene therapies recognizing the potential for financial windfalls. Last year, the Alliance for Regenerative Medicine estimated more than 2,200 clinical trials were testing these types of treatments globally, and over $12 billion was being invested. Investment firms are also betting big on the new therapies. In 2023, Goldman Sachs announced it closed its first-ever life sciences fund - worth $650 million - to invest money in genetic medicine, cell therapies, immunotherapies, synthetic biology and emerging biotechnologies.

Officials within the FDA have expressed their commitment to the rapid review and accelerated approval of these therapies. As a result, we may end up with many more high-cost therapies on the market with incomplete evidence on safety, efficacy and long-term effects. Policymakers and stakeholders meanwhile are grappling with a way to pay for multi-million dollar therapies, as the current payment models will fail. Simply stated, the nation is not prepared for the onslaught of cell and gene therapies likely to emerge in the years to come.

ACHP recognizes that these new treatments will require changes to how we think about and approach coverage and payment. To that end, our member companies have engaged clinical and pharmacy experts, patients and others concerned to explore access, coverage and payment options. As ACHP displayed in its response to Senate HELP Committee Ranking Member Cassidy's request for information, it is necessary for policymakers consider the exorbitant price of these therapies and for the federal government, drug companies, providers and payers to collaborate on sustainable financing mechanisms.

This is an issue of national concern that requires congressional oversight and engagement. In the past, Congress has always risen to the occasion when confronted with the challenges of high-cost drugs. The Hatch-Waxman Act and the Biologics Price Competition and Innovation Act demonstrate Congress can craft policy solutions that address the need for patient access and affordable prices. Congress must once again come together to take similar action to address cell and gene therapies.

ACHP looks forward to working with you to improve access to affordable and potentially life-saving cell and gene therapies. Please contact Dan Jones, ACHP Senior Vice President for Federal Affairs, djones@achp.org, with any questions.

Sincerely,

Ceci Connolly

Ceci Connolly
President and CEO
ACHP