Institute for Gene Therapies

909 E Street NW, 2nd Floor
Washington D.C. 20004

April 24, 2023

The Honorable Brett Guthrie
2434 Rayburn House Office Building
Washington, DC 20515

The Honorable Jake Auchincloss
1524 Longworth House Office Building
Washington, DC 20515

The Honorable Anna Eshoo
202 Cannon House Office Building
Washington, DC 20515

The Honorable John Joyce
152 Cannon House Office Building
Washington, DC 20515

The Honorable Mariannette Miller-Meeks
1716 Longworth House Office Building
Washington, DC 20515

The Honorable Scott Peters
1201 Longworth House Office Building
Washington, DC 20515

RE: Introduction of the Medicaid VBPs for Patients Act, or the MVP Act (H.R. 2666)

Dear Representatives Guthrie, Eshoo, Miller-Meeks, Auchincloss, Joyce and Peters:

The Institute for Gene Therapies (IGT) is grateful for your leadership to help ensure patients have access to innovative gene therapies and thanks you for authoring the MVP Act.

Gene therapies are fundamentally different from traditional biologics taken over the course of a patient's lifetime to address the symptoms of disease. With gene therapy, we now have the ability to target the source of many rare diseases at the genetic level – often with one long-lasting dose. This creates unique opportunities for patients, their families, and the providers managing their care. This innovation also presents unique reimbursement challenges that must be addressed in order to ensure these transformative treatments can be delivered to patients.

Getting the coverage and reimbursement right for gene therapies is essential and requires a keen understanding of the value these therapies present. We are pleased to see that you recognize this reality and are taking action to address access barriers that could delay the delivery of current and future potentially life-changing therapies to patients.

IGT supports flexibility in defining value-based purchasing (VBP) arrangements to accommodate the expected growth in gene therapies approved by the FDA. As the field of gene therapies advances and matures, it's critical that our healthcare system encourages payment approaches that accommodate the variety of gene therapies that will be available to address the unique needs of different patient communities. The bipartisan MVP Act builds on the work of the Centers for Medicare & Medicaid Services (CMS), which has established clear pathways to VBP arrangements for manufacturers, payers, and providers where outcomes-based approaches can be practicably implemented.

IGT continues our work to develop a sustainable, flexible, and permanent payment pathway reflective of the scientific advancements resulting in gene therapy breakthroughs. Your work is critical to creating an environment where our reimbursement and regulatory infrastructure can keep up with scientific breakthroughs so significantly impactful for patients, their families and caregivers.

We look forward to working with Congress and stakeholders across the healthcare system to build support for this important piece of legislation.

Sincerely,

The Honorable Erik Paulsen
Chairman
Institute for Gene Therapies

Members of the Institute for Gene Therapies Corporate and Patient Advocacy Advisory Councils:

Khrystal Davis, Rare Disease Advocate, Mother of son w/SMA, Founder of Texas Rare Alliance

Jenn McNary, Patient Advocate & Consultant, Founder, One Rare

Lauren Holder, Huntington's Disease Patient Advocate and Producer/Host of Help 4 HD Live Podcast

Rolf Benirschke, Survivor and Patient Advocate Crohn's Disease, Ulcerative Colitis, Colorectal & Bladder Cancer