

January 29, 2019

Senator Bill Cassidy
520 Hart Senate Office Building
Washington, DC 20515

Senator Mark Warner
475 Russell Office Building
Washington, DC 20515

Dear Senator Cassidy and Senator Warner,

As representatives of the undersigned patient advocacy organizations, we are writing to express support for your work to craft legislation to remove legal and regulatory barriers that effectively preclude the adoption of value-based payment models within the Medicare and Medicaid programs.

The adoption of value-based payment models and other innovative reimbursement mechanisms within federal programs are needed due to the emergence of new and innovative therapies, including cellular therapies and gene-based medicines, that have the potential to treat or even cure a variety of life-threatening diseases and disorders for which there are currently no or inadequate treatments. However, current reimbursement methodologies are not set up to recognize the high-value, durable nature of these cutting-edge medicines, or to take into account the innovative payment plans being developed, which leaves us concerned that patient access to them could be greatly threatened. This is why your efforts are so important.

There are hundreds of these revolutionary medicines in development and they hold the potential to provide hope where there might currently be none, dramatically improving patients' health outcomes and quality of life. Any hurdles that could needlessly impede a patient's ability to access them must be addressed and we appreciate your efforts to do so.

Sincerely,

CureDuchenne
Cure Sanfilippo Foundation
Debra of America
Friedreich's Ataxia Research Alliance
Global Genes - Allies in Rare Disease
MLD Foundation
MTM-CNM Family Connection
Myotonic Dystrophy Foundation
Parent Project Muscular Dystrophy – PPMD
Prevent Cancer Foundation
Power for Parkinson's
Soft Bones, The Hypophosphatasia Foundation
The Michael J. Fox Foundation
The Joshua Frase Foundation