



July 1, 2024

The Honorable Cathy McMorris Rodgers
 Chairman, House Energy & Commerce Committee
 U.S. House of Representatives
 2188 Rayburn HOB
 Washington, DC 20515

The Honorable Frank Pallone
 Ranking Member, House Energy &
 Commerce Committee
 U.S. House of Representatives
 2107 Rayburn HOB
 Washington, DC 20515

The Honorable Brett Guthrie
 Chairman, House Energy &
 Commerce Subcommittee on Health
 U.S. House of Representatives
 2434 Rayburn HOB
 Washington, DC 20515

The Honorable Anna Eshoo
 Ranking Member, House Energy &
 Commerce Subcommittee on Health
 U.S. House of Representatives
 202 Canon HOB
 Washington, DC 20515

cc:

The Honorable Mike Johnson
 Speaker of the House
 U.S. House of Representatives
 H-232, The Capitol
 Washington, DC 20515

The Honorable Hakeem Jeffries
 House Democratic Leader
 U.S. House of Representatives
 H-204, The Capitol
 Washington, DC 20515

Re: Support H.R. 5547 – the MINI Act – and sustain hope for patients

Dear Chairman McMorris Rodgers, Ranking Member Pallone, Subcommittee Chair Guthrie and Subcommittee Ranking Member Eshoo:

We, the undersigned organizations, represent patients living with difficult-to-treat diseases. We write today urging you to support H.R. 5547, the Maintaining Investment in New Innovation Act, which encourages and protects innovative medication for patients like us.

People with difficult-to-treat diseases put their hope in medical research and innovation – and for good reason. Each new decade has brought new advances and new technology that changes and saves lives. That’s a trend we want to continue.

Whether it’s a patient at risk of amputation due to peripheral arterial disease, a family impacted

by Lp(a) or familial hypercholesterolemia, or a patient newly diagnosed with a rare condition, advanced treatments play a critical role. That's true of emerging therapies like genetically targeted technologies, which are sophisticated treatments that target certain rare and deadly conditions.

How the MINI Act Would Help Patients

The MINI Act would promote continued medical innovation by ensuring that drugs made with genetically targeted technologies are eligible for Medicare negotiation after 11 years on the market rather than seven, under the Inflation Reduction Act. Similar to biologic drugs, drugs made with genetically targeted technologies are highly innovative drugs based on complex chemical synthesis that quite simply take longer to develop. This cutting-edge technology was awarded the Nobel Prize in Medicine in 2006 and has the potential to make a real difference in the lives of patients.

We, the undersigned patient organizations, know that this timeline disincentivizes continued investment in nascent technology that fosters hope for our communities.

In short, genetically targeted technologies could quickly become a dying class of drugs just as they are starting to show promise for patients.

Time is precious for the patients who stand to benefit from complex, groundbreaking treatments. That's why the MINI Act would move genetically targeted technologies under the same guidelines as large-molecule biologics for the purposes of Medicare drug price negotiation. This would allow researchers an extra four years to continue researching and finding more solutions for patients.

Conclusion

By making this targeted change, you can maintain hope for patients and encourage ongoing development of life-changing treatments. We urge you to co-sponsor the MINI Act.

Sincerely,

Amputee Coalition

Aimed Alliance

Cure Duchenne

Dravet Syndrome Foundation

Family Heart Foundation

Hereditary Neuropathy Foundation

KIF1A.org

Nurses Organization of Veterans Affairs (NOVA)

Spina Bifida Association

The Mended Hearts, Inc.

WomenHeart: The National Coalition for Women with Heart Disease