national down syndrome society
ndss®

March 5, 2025

The Honorable Thom Tillis
113 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Ted Budd
304 Russell Senate Office Building
Washington, DC 20510

The Honorable Marsha Blackburn
357 Dirksen Senate Office Building
Washington, DC 20510

The Honorable James Lankford
731 Hart Senate Office Building
Washington, DC 20510

The Honorable Steve Daines
320 Hart Senate Office Building
Washington, DC 20510

The Honorable Gregory Murphy
407 Cannon House Office Building
Washington, DC 20515

The Honorable Donald Davis
1123 Longworth House Office Building
Washington, DC 20515

The Honorable Richard Hudson
2112 Rayburn House Office Building
Washington, DC 20515

Dear Senators Tillis, Budd, Blackburn, Lankford, and Daines and Representatives Murphy, Davis, and Hudson:

The National Down Syndrome Society (NDSS) empowers individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions. Today we write in strong support of the *Ensuring Pathways to Innovative Cures* (EPIC) Act (S. 832/H.R. 1492). If passed, this bill would ensure that small-molecule drugs such as pills, tablets, and patches are not deprioritized in research and funding compared to more invasive treatment options.

The Inflation Reduction Act (IRA), which was signed into law in 2022, included pricing controls for certain drugs and therapeutics. However, before these price controls go into effect, new medicines get a “grace period” which gives developers time to earn a return on their investments and further incentivizes the drug development that individuals with Down syndrome and other disabilities benefit greatly from. For large-molecule drugs, which are often administered in hospitals and physicians’ offices, the IRA grants a

13-year period after FDA approval before the new drugs and treatments would be subjected to the pricing caps. However, small-molecule drugs, such as pills, tablets, and patches, only get a 9-year grace period before they are subjected to government pricing caps.[1] The implications of that four-year gap are profound and misaligned with the needs of patients and families. It is estimated that over the next 20 years, this penalty on the development of small-molecule drugs will result in 188 fewer small-molecule treatments reaching patients.[2]

Individuals with Down syndrome often rely on and benefit greatly from small-molecule drugs. Traveling to hospitals isn't always accessible for individuals with disabilities, especially in rural areas. Furthermore, small-molecule drugs that can be administered at home alleviate the cost and inconvenience of travel, allowing patients to maintain daily activities. For individuals with Down syndrome, who may already struggle with invasive medical procedures and unfamiliar environments, the additional complexity that more intensive treatments pose can be overwhelming.

Beyond the increased accessibility that small-molecule drugs can provide to individuals with Down syndrome, these drugs are also at the forefront of addressing some of the most critical health needs of the Down syndrome community. The Down syndrome community has an over 90% chance of developing Alzheimer's disease over their lifetime, a much higher rate than for the general population.[3] Small-molecule drugs represent one possible treatment option that could have a profound impact. Unlike large-molecule drugs such as biologics, these medications can cross the blood-brain barrier, targeting the root causes of dementia.[4] People with Down syndrome also suffer from hypothyroidism, heart anomalies, blood disorders, infections, and epilepsy at higher rates than the general population – all areas that could benefit from small-molecule research.

If passed, the EPIC Act would ensure that two equally important and impactful types of drugs – small and large molecule drugs – are treated equally under the law and the development of one is not prioritized over the other. We thank you for your leadership on this critical issue and urge the United States Congress to take swift action to rectify this issue.

Sincerely,

Kandi Pick

Kandi Pickard
President and CEO
National Down Syndrome Society

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[1] https://www.kff.org/medicare/issue-brief/explaining-the-prescription-drug-provisions-in-the-inflation-reduction-act/

[2] https://ecchc.economics.uchicago.edu/2023/10/09/policy-brief-the-potentially-larger-than-predicted-impact-of-the-ira-on-small-molecule-rd-and-patient-health-2/

[3] https://www.medicalnewstoday.com/articles/down-syndrome-and-alzheimers#prevalence

[4] https://pmc.ncbi.nlm.nih.gov/articles/PMC4064947/