

2026 Regular Session

HOUSE RESOLUTION NO. 401

BY REPRESENTATIVES BEAULLIEU, BRYANT, JACOB LANDRY, AND ST. BLANC

CONGRESS: Memorializes the United States Congress to work towards a cure for Sanfilippo Syndrome

1 A RESOLUTION

2 To memorialize the United States Congress to work towards a cure for Sanfilippo
3 Syndrome.

4 WHEREAS, Sanfilippo syndrome, also known as "childhood Alzheimer's" or
5 "childhood dementia", is a rare group of inherited lysosomal storage disorders that mainly
6 affect a child's central nervous system; and

7 WHEREAS, Sanfilippo syndrome causes multiple cognitive, behavioral, and physical
8 symptoms that progressively get worse with time, with symptoms leading to premature
9 death; and

10 WHEREAS, this syndrome occurs when there is a deficiency in one of four enzymes
11 that affect the breakdown of heparan sulfate, a complex carbohydrate, leading to the buildup
12 in a child's cells, tissues, and organs, ultimately damaging them; and

13 WHEREAS, according to the Cure Sanfilippo Syndrome Foundation, the disease is
14 estimated to affect one in every seventy thousand births, and due to its rarity and mimicry
15 of other conditions, such as attention deficit/hyperactivity disorder (ADHD) or autism,
16 diagnosis is often delayed; and

17 WHEREAS, there are multiple treatments for symptom management to maintain
18 one's quality of life and prevent further complications, however, depending on the subtype,
19 the average life expectancy ranges from early teens to early thirties; and

20 WHEREAS, Shepard Guillory, son of Lafayette residents Natalie and Caleb Guillory,
21 brother of Ami Guillory, and grandson of Freddie and Janita DeCourt and Michelle Guillory

1 and the late Scott Guillory, was born on January 23, 2025, and later diagnosed with
2 Sanfilippo syndrome on April 24, 2026; and

3 WHEREAS, scientific research and clinical trials are being conducted by multiple
4 institutions to further understand and develop a cure for the disease, there is still a need for
5 funding and general support for these projects; and

6 WHEREAS, families, like the Guillorys, facing the challenges of Sanfilippo
7 syndrome continue to advocate with urgent hope and resilience, looking toward a future
8 where breakthroughs will offer a cure for their children; and

9 WHEREAS, state legislatures have a long-standing role in urging federal action on
10 matters of national health importance and in advocating for policies that advance medical
11 research and public welfare.

12 THEREFORE, BE IT RESOLVED that the House of Representatives of the
13 Legislature of Louisiana does hereby memorialize the Congress of the United States to
14 prioritize research, clinical trials, and treatment development related to the cure of Sanfilippo
15 syndrome.

16 BE IT FURTHER RESOLVED that the House of Representatives does hereby
17 extend its profoundest support, deepest encouragement, and most sincere wishes to Shepard
18 and the Guillory family as they face the daily challenges of Sanfilippo syndrome with
19 extraordinary grace, strength, and hope for a future cure.

20 BE IT FURTHER RESOLVED that a copy of this Resolution be transmitted to the
21 presiding officers of the Senate and the House of Representatives of the Congress of the
22 United States of America, the Louisiana congressional delegation, and the parents of
23 Shepard Guillory, Natalie and Caleb Guillory.

DIGEST

The digest printed below was prepared by House Legislative Services. It constitutes no part of the legislative instrument. The keyword, one-liner, abstract, and digest do not constitute part of the law or proof or indicia of legislative intent. [R.S. 1:13(B) and 24:177(E)]

HR 401 Original

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Beaulieu

Memorializes the United States Congress to prioritize research and clinical trials related to the cure of Sanfilippo Syndrome.