

2026 Regular Session

HOUSE RESOLUTION NO. 401

BY REPRESENTATIVES BEAULLIEU, BILLINGS, BOUDREAUX, BRYANT,
BUTLER, CHASSION, COATES, EGAN, KNOX, JACOB LANDRY, MILLER,
SPELL, ST. BLANC, AND TAYLOR

A RESOLUTION

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

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

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

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

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

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

WHEREAS, Shepard Guillory, son of Lafayette residents Natalie and Caleb Guillory, brother of Ami Guillory, and grandson of Freddie and Janita DeCourt and Michelle Guillory and the late Scott Guillory, was born on January 23, 2024, and later diagnosed with Sanfilippo syndrome on April 24, 2026; and

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

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

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

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

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

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

SPEAKER OF THE HOUSE OF REPRESENTATIVES