

# Federal Public Health Policy 2020 Brings Focus on Sudden Unexplained Infant Death (SUID) and Infant Health Outcomes

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*The Alliance for Patient Access ([allianceforpatientaccess.org](http://allianceforpatientaccess.org)), founded in 2006, is a national network of physicians dedicated to ensuring patient access to approved therapies and appropriate clinical care. AfPA accomplishes this mission by recruiting, training and mobilizing policy-minded physicians to be effective advocates for patient access. AfPA is organized as a non-profit 501(c)(4) corporation and headed by an independent board of directors. Its physician leadership is supported by policy advocacy management and public affairs consultants. In 2012, AfPA established the Institute for Patient Access (IfPA), a related 501(c)(3) non-profit corporation. In keeping with its mission to promote a better understanding of the benefits of the physician-patient relationship in the provision of quality healthcare, IfPA sponsors policy research and educational programming.*



As Congress returned to Washington, DC, after the new year, healthcare continues to be a major focus, including two pieces of legislation directly related to infant mortality and infant health outcomes:

- H.R. 2271, the Scarlett's Sunshine on Sudden Unexpected Death Act;
- H.R. 4801, the Healthy Start Reauthorization Act.

A January 8th U.S. House Energy and Commerce Committee Health Subcommittee hearing titled, "Legislation to Improve Americans' Health Care Coverage and Outcomes," shed light on these bills.

## H.R. 2271

H.R. 2271, the Scarlett's Sunshine on Sudden Unexpected Death Act, advances current efforts to further understand both sudden unexplained infant death (SUID) and sudden unexplained death in childhood (SUDC). H.R. 2271, introduced by Congresswoman Gwen Moore (D-WI), would improve the comprehensiveness and standardization of child and infant death investigations. The legislation was introduced in April 2019 and, to date, has the bipartisan support of 62 cosponsors.

Senator Bob Casey (D-PA) and recently retired Senator Johnny Isakson (R-GA) have introduced a related bill in the Senate, S. 1130. Senator Casey noted in a press release announcing the introduction of the legislation that 3,600 infants each year pass away from "unexplained causes."

<https://www.casey.senate.gov/newsroom/releases/casey-colleagues-introduce-bipartisan-bill-to-address-unexpected-child-infant-deaths>

The legislation is named for 16 month-old Scarlett Pauley, who died suddenly in January 2017. According to her parents, Stephanie Zarecky and Ryan Pauley explained: Scarlett was a healthy, thriving baby who went to sleep and never woke up.

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Many cases like baby Scarlett's result in parents learning only an "unknown" or ambiguous cause of their child's death, where the tragedy may have been preventable by screenings or research into sleep-related disorders. H.R. 2271 and S. 1130 would require the Centers for Disease Control and Prevention (CDC) to review and improve procedures for the comprehensive death scene investigations involving cases of SUID and SUDC. The hope is that more medical research, data collection, and procedural improvements in crime scene investigations will lead to a better understanding of and even prevent future SUID and SUDC events. The bill also calls for additional family support services for those who have lost a child to SUID and SUDC.

Endorsements for the bill have come from: the American Academy of Pediatrics (AAP), March of Dimes, Children's Hospital Association, Cribs for Kids, First Candle, SUDC Foundation, KID: Fighting for Product Safety, and the Aaron Matthew SIDS Research Guild of Seattle Children's Hospital.

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## H.R. 4801

The Subcommittee also considered H.R. 4801, the Healthy Start Reauthorization Act, to enhance programs that support perinatal health, reduce infant mortality, and improve long-term health outcomes. House Energy and Commerce Chairman Frank Pallone, Jr. (D-NJ) noted that “Despite serving communities that have had much higher rates of infant mortality, Healthy Start grantees have shown their ability to bring their communities’ overall infant mortality rate below the national average, demonstrating the program’s success and the need to expand and strengthen it.”

<https://energycommerce.house.gov/newsroom/press-releases/pallone-remarks-at-hearing-on-legislation-to-improve-americans-health-care>

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The bill provides for the reauthorization of the Healthy Start Program for five years at \$135 million annually, an increase of \$15 million per year above the most recent authorized level.

The Healthy Start Program “provides grants to state and local community organizations in targeted areas with infant mortality rates that are at least 1.5 times the national average and/or with high indicators of poor perinatal outcomes, particularly among black and other disproportionately affected populations.”

<https://energycommerce.house.gov/sites/democrats.energy-commerce.house.gov/files/documents/Memo%2010819%20hearing%20Legislation%20to%20Improve%20Americans%20Health%20Care%20Coverage%20and%20Outcomes.pdf>

This legislation was introduced in October 2019 in both the House and Senate. The Healthy Start Program was last reauthorized in 2008.

## More Information

For more information, a House Energy & Commerce Health Subcommittee hearing memorandum for January 8, 2020, can be found here:

<https://energycommerce.house.gov/sites/democrats.energy-commerce.house.gov/files/documents/Memo%20010819%20hearing%20Legislation%20to%20Improve%20Americans%20Health%20Care%20Coverage%20and%20Outcomes.pdf>

The bills still need to pass through Health Committees and both the House and Senate to become law. To contact your lawmaker and voice your support for either of these bills, please visit [www.house.gov](http://www.house.gov) and [www.senate.gov](http://www.senate.gov).

#### References:

1. <https://www.casey.senate.gov/newsroom/releases/casey-colleagues-introduce-bipartisan-bill-to-address-unexpected-child-infant-deaths>
2. <https://energycommerce.house.gov/newsroom/press-releases/pallone-remarks-at-hearing-on-legislation-to-improve-americans-health-care>
3. <https://energycommerce.house.gov/sites/democrats.energycommerce.house.gov/files/documents/Memo%20010819%20hearing%20Legislation%20to%20Improve%20Americans%20Health%20Care%20Coverage%20and%20Outcomes.pdf>
4. <https://energycommerce.house.gov/sites/democrats.energycommerce.house.gov/files/documents/Memo%20010819%20hearing%20Legislation%20to%20Improve%20Americans%20Health%20Care%20Coverage%20and%20Outcomes.pdf>

*The author has not indicated any disclosures.*

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