

# Infantile spasms: Speeding referrals for all infants

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Infantile epileptic spasms syndrome (IESS), often called infantile spasms, is the most common form of epilepsy seen during infancy. Prompt diagnosis and referral to a neurologist are essential.

However, research suggests infants are likely to experience delays in referral to a neurologist if their families are from historically marginalized racial/ethnic backgrounds. A new open-access training module for front-line providers from OPENPediatrics, an online learning community launched by Boston Children's Hospital, aims to change that.

The free, publicly accessible [Infantile Spasms curriculum](#) includes short lectures and videos illustrating [infantile spasms](#) to help primary care providers identify IESS and ensure prompt treatment. Through self-assessments at the end of each chapter, clinicians can test their diagnostic skills and hone their instincts.

[A national study](#) in 2022 found that Black [children](#) and children with public insurance are less likely to receive a standard treatment course for infantile epileptic spasms as compared with white children and children with private insurance.

That prompted Boston Children's neurology fellow Christina Briscoe Abath, MD, and her mentor Chellamani Harini, MD, to take a closer look at care for infantile spasms at Boston Children's, which took part in the [national study](#).

"We needed to know if children at our center were getting the appropriate treatment for IESS based on their race or ethnicity, so we could promptly address it if so," Briscoe Abath says.

The study, [published in the journal \*Epilepsia\*](#), identified 100 children at Boston Children's Hospital with new-onset IESS diagnosed between 2019 and 2022.

The researchers found that children with Black, Indigenous, and People of Color (BIPOC) parents or guardians were more likely to experience

delays of more than seven days in referral from [primary care](#) to a neurologist, as compared with non-Hispanic [white children](#). This was true even after controlling for median household income, language, distance from the hospital, and clinical factors.

These findings were the motivation behind the OPENPediatrics educational module. Critical to the module's success, several families contributed photos and videos of their children to demonstrate the wide range of how IESS can present. Based on the research, the module also invites clinicians to consider the reasons for inequities in the evaluation of IESS and how they might act to decrease the disparities.

The multi-disciplinary team formed from this initiative continues to meet every other week and is conducting a qualitative research study to uncover the root causes of care inequities. The findings will be used to improve systems of care through quality improvement methodology.

"We have a moral imperative to address inequities in care affecting children with IESS," says Briscoe Abath. "We need to work together with families affected by IESS to better understand how to address inequities effectively and meaningfully."

**More information:** Christina Briscoe Abath et al, Delays to care in infantile epileptic spasms syndrome: Racial and ethnic inequities, *Epilepsia* (2023). [DOI: 10.1111/epi.17827](https://doi.org/10.1111/epi.17827)

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