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SADS Foundation to Present Proposed ICD-10 Codes to the CDC in September 2025

(Salt Lake City, UT) – August 19, 2025 – The Sudden Arrhythmia Death Syndromes (SADS) Foundation will present three proposed additions to the International Classification of Diseases, Tenth Revision (ICD-10), to the U.S. Centers for Disease Control and Prevention (CDC) on **September 9-10, 2025**. The proposed codes will provide formal classification for three inherited heart rhythm conditions:

- Catecholaminergic Polymorphic Ventricular Tachycardia (**CPVT**).
- Brugada Syndrome (**BrS**).
- Arrhythmogenic Cardiomyopathy (**ACM**), also known as Arrhythmogenic Right Ventricular Cardiomyopathy (**ARVC**).

These new codes will help advance research; improve recognition, diagnosis, and insurance reimbursement for these conditions; and pave the way for approval of new therapies.

The SADS Foundation will lead the presentation, supported by expert speakers for each condition:

- **Prince Kannankeril, MD, MSCI**, Professor of Pediatrics and Co-Director of the Vanderbilt Center for Pediatric Precision Medicine and **Andrew Landstrom, MD, PhD**, Duke University School of Medicine will speak on CPVT.
- **Dan Roden, MD**, Senior Vice-President for Personalized Medicine and Professor of Medicine, Pharmacology, and Biomedical Informatics, Vanderbilt University Medical Center and **Gregory Webster, MD, MPH**, Section Chief of Electrophysiology at Lurie Children's Hospital of Chicago and Assistant Professor of Pediatrics (Cardiology) at Northwestern University Feinberg School of Medicine, will present on Brugada Syndrome.
- **Brittney Murray, MS, CGC**, genetic counselor at Johns Hopkins Hospital and **Crystal Tichnell, MGC, RN**, Johns Hopkins Hospital will present on ACM.

Research in the inherited arrhythmia field is progressing rapidly. However, CPVT, Brugada Syndrome, and ACM currently lack dedicated ICD-10 codes. These codes will help pave the way for insurance coverage of emerging treatments - therefore helping to advance research.

“Having official ICD-10 codes for these three conditions will help clear the path for FDA-approved treatments,” said **Dr. Michael Ackerman**, M.D., Ph.D., Mayo Clinic and President of the Board of Directors at the SADS Foundation. “We are proactively removing a critical barrier for patients who urgently need new therapies.”

In addition to supporting the creation of new treatments, ICD-10 codes help patients and families access essential care for their condition. These classifications are essential for tracking each diagnosis, billing insurance, and helping patients access appropriate therapies and specialists.

“Without specific ICD-10 codes, many families face delays and denials in care, including coverage for lifesaving devices like in-home AEDs,” said **Genevieve Echols, RCIS**, Family Support, Advocacy and Research Director at the SADS Foundation. “With these codes, we hope to ensure smoother navigation through the healthcare system and better access to experts and appropriate treatment.”

The SADS Foundation expects a decision from the CDC regarding the approval and implementation of these codes in the first quarter of 2026.

This effort has been made possible through the generous support of our corporate partners: **Lexeo Therapeutics, Rocket Pharmaceuticals and Solid Biosciences.**

About the SADS Foundation

Founded in 1991, the **Sudden Arrhythmia Death Syndromes (SADS) Foundation** is a community of families and medical professionals committed to saving lives and advancing care for those with genetic heart rhythm conditions. Learn more at StopSADS.org.

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