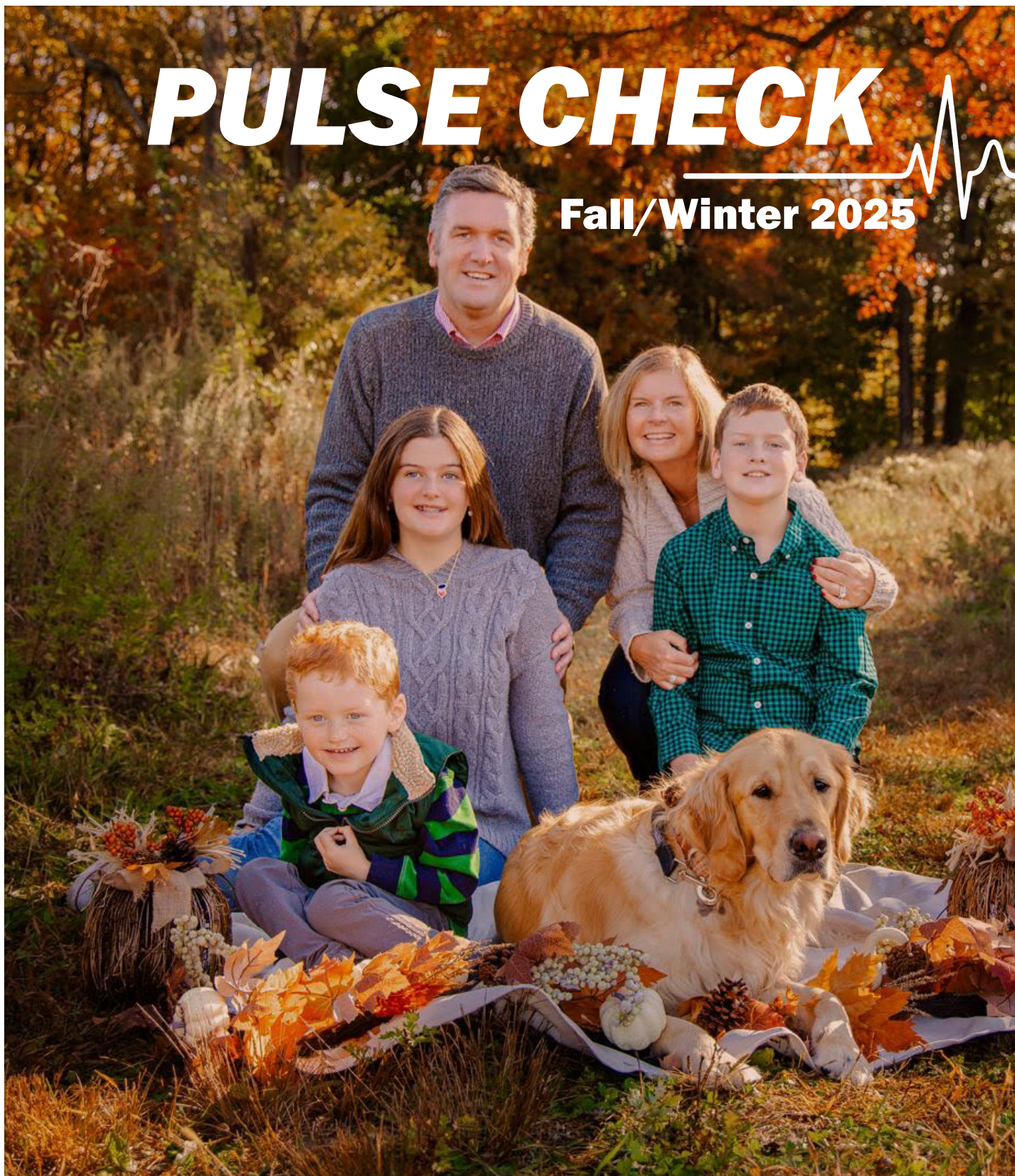


PULSE CHECK

Fall/Winter 2025



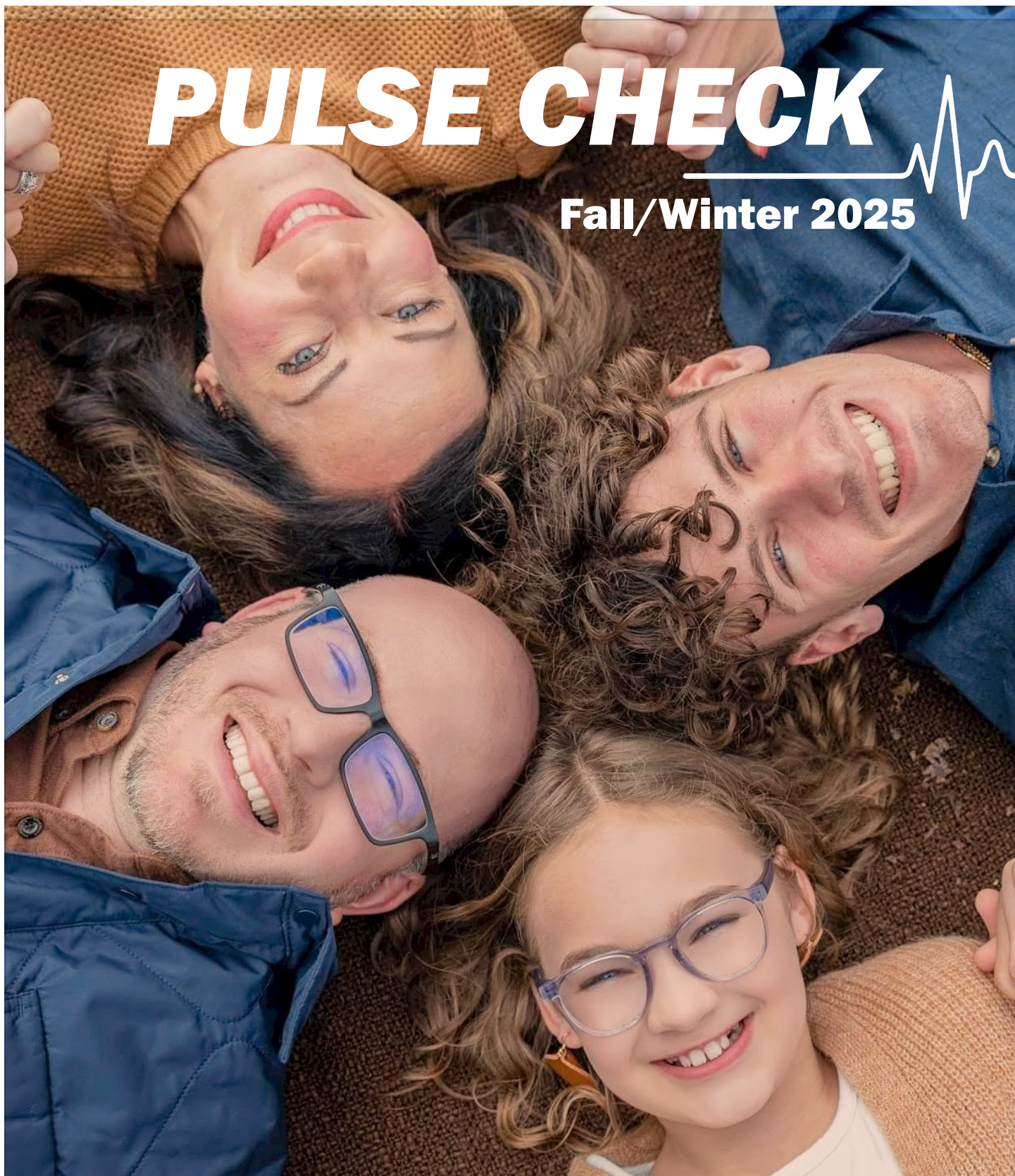
In this issue:

New condition coding | meet our new CEO | stories from the heart



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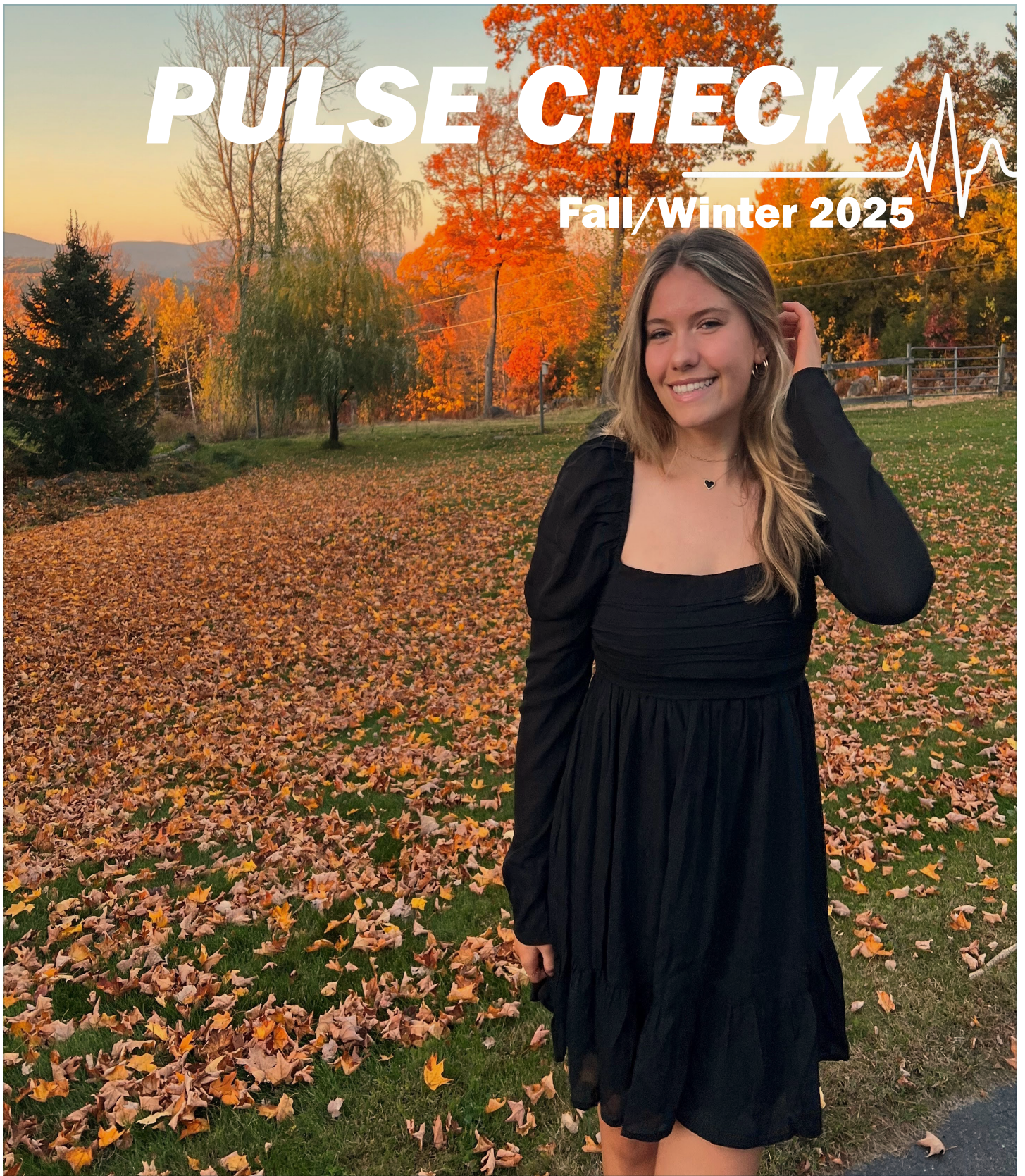
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OUR MISSION

At the **SADS Foundation**, our mission is to empower people with genetic heart conditions – including channelopathies and cardiomyopathies – to live and thrive, beyond their diagnosis.

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Welcome to the fall/winter edition of our newsletter, **Pulse Check**. This is Walker Frahm, the new CEO here at SADS!

I stepped into this role in May, as Alice Lara retired after 24 years of visionary leadership. I join our community in expressing my deepest thanks for the strong foundation Alice built at SADS—one that uniquely combines deep compassion with world-class expertise.

From day one, I've been inspired by the urgency and generosity of spirit that define this community—and I feel privileged to be a part of it.

A Personal Connection

Families, medical professionals, staff, and volunteers all work tirelessly to share knowledge, connect others to care, push research forward, and ensure no one is alone in this often scary journey.

Throughout my career, I've supported families dealing with profound loss leading refugee aid and crisis response efforts in twenty countries. I have witnessed how timely information and coordinated action can save lives.

But for me, the mission of SADS is personal. When our daughter died from an undiagnosed cardiac incident, those lessons hit home in the most immediate of ways. Now, SADS gives me the opportunity to use these skills—strategic thinking, partnership-building, and advocacy—to help families avoid the kind of loss too many of us, my own family included, have experienced.

Looking Ahead

Looking ahead, I'm especially energized by the growing momentum around research and therapeutic development for SADS conditions. We're seeing new interest from industry partners developing more targeted medications and therapies. While it's still early, there's real energy building! We're working proactively to help translate that momentum into action by centering patient voices in drug development, expanding access to genetic testing, and launching a SADS registry to drive research and improve care.

Together, we have so much to celebrate and still so much to pursue. I'm incredibly grateful to be on this journey with all of you—and eager to listen, learn, and lead alongside this remarkable community. Please feel free to reach out to me directly any time at walker@sads.org. I'd love to hear from you.

ON THE COVER: "In the beginning, I wanted to hide Patrick's diagnosis. I didn't know who I was anymore. But now, I want the world to hear about his heart for progress, connection, a chance at treatment, and ultimately for a cure."



Read Susan and Patrick's story at sads.org.



Allie's family, pictured above, faced multiple insurance denials due to the lack of an ICD-10 code for CPVT.

SADS Foundation Spearheads Three New ICD-10 Codes

In September 2025, the SADS Foundation met with the CDC to introduce ICD-10 (classification) codes for CPVT, ACM, and Brugada Syndrome.

What are ICD-10 codes, and why are they important?

ICD-10 codes are what your doctor puts in your medical chart as your specific diagnosis. They use this code to bill insurance and get the proper treatment for your condition covered. These codes will help pave the way for insurance coverage of emerging treatments - therefore helping to advance research.

| “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 Genevie, Family Support, Advocacy & Research Director. “With these codes, we hope to ensure smoother navigation through the healthcare system and better access to experts and appropriate treatment.”

Thank you to our corporate partners whose support helped make this meeting possible.



Three Ways ICD-10 Codes Will Transform Your Care

Helps smooth the process of insurance approvals for needed treatments

Makes diagnosing, treating, and referring easier for doctors

Accelerates research by helping researchers understand how many people truly have these conditions

Learn more at sads.org/icd10code.

What's new in treatment for rare hearts?



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*with Andrew Landstrom, MD, PhD
Duke University
SADS Foundation Board Member*

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Learn more at sads.org/research.



Gene Therapy: What is it?

Why does it matter?

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| POP QUOTE



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Drs. Georgia Brugada and Michael Ackerman

Snapshots from 2025 advocacy. From left to right: Sed ut perspiciatis unde omnis iste natus error sit voluptatem accusantium doloremque laudantium. Sed ut perspiciatis unde omnis iste natus error sit voluptatem accusantium doloremque laudantium.

Five quick facts about genetic testing