SADS Foundation Becomes the Foundation for Inherited Arrhythmias (FIA)

A trusted patient advocacy organization takes a new name that reflects decades of scientific progress and the families at the center of its mission.

SALT LAKE CITY — The SADS Foundation, the leading patient advocacy organization for inherited heart rhythm conditions, today announced that it is now operating as the Foundation for Inherited Arrhythmias (FIA). The new name reflects both the progress of the field and the foundation's unchanging commitment to the patients and families it serves.

From Loss to Hope

When the foundation was established thirty-five years ago, inherited arrhythmias were poorly understood. Only a few genes had been discovered, and families often learned of a diagnosis only after the sudden death of a loved one, with little reliable information and nowhere obvious to turn. Decades of research and growing clinical awareness have changed what is possible. Many inherited arrhythmia conditions can now be identified through genetic testing before a cardiac event occurs, and individuals who receive a timely diagnosis and appropriate care can and do live long, full lives.

“The families who came to the SADS Foundation in those early moments of grief became the heart of this organization. Supporting families through loss and preventing tragedies remain at the center of everything FIA does,” said **Walker Frahm, CEO of the Foundation for Inherited Arrhythmias**. “This name change also reflects how far the field has come, and how much more is possible for every person navigating an inherited arrhythmia diagnosis.”

A Lifeline That Grew into a Global Community

What began as a lifeline for grieving families is now one of the largest communities of its kind. FIA's network includes more than 18,000 patients and family members and 5,100 clinicians. Each year, the foundation provides personalized medical navigation to more than 1,100 patients, connects families to a referral network of over 150 specialists, and reaches more than 1.5 million people through digital outreach efforts. FIA partners with dozens of active research studies advancing new therapies and quality-of-life improvements, has successfully advocated to the CDC for new diagnostic codes, and has brought patients' voices directly to the FDA and drug developers to help shape how new treatments are developed and evaluated.

A Name That Reflects the Community and the Science

Families shared that the original name, Sudden Arrhythmia Death Syndromes, often created barriers to seeking support, emphasizing worst-case outcomes at the very moment when many families most needed to hear about the possibility of effective treatment and a full life. Clinicians noted that “inherited arrhythmias” is already standard terminology in cardiology. The change to become the Foundation for Inherited Arrhythmias makes the organization easier to find, easier to recommend, and easier to recognize as a clinical partner.

“From a research perspective, this is an exciting moment in inherited arrhythmia care,” said **Dr. Michael Ackerman, M.D., Ph.D., FIA President and Genetic Cardiologist at Mayo Clinic**. “Science is advancing rapidly, new therapies are on the horizon, and the future for patients and families is more hopeful than it has ever been. The change to become the Foundation for Inherited Arrhythmias reflects that momentum, and a deepening commitment to partnering with clinicians, researchers, and families to advance care.”

Same Mission. Stronger Partnerships.

FIA's programs, team, and mission remain unchanged. For patients and families, FIA continues to offer expert-backed one-on-one support, condition-specific education and resources, peer support groups, and educational webinars. For the clinical community, FIA provides peer consultation on challenging cases, CME-accredited medical education webinars and conferences, curated guidance on current standards of care, genetic testing and medication information, patient-facing resources that clinicians can share directly with their patients, and support for clinical trial recruitment. FIA specializes in inherited cardiomyopathies and channelopathies, including long QT syndrome, Brugada syndrome, CPVT, arrhythmogenic cardiomyopathy (ACM), and related conditions.

About the Foundation for Inherited Arrhythmias

The Foundation for Inherited Arrhythmias (FIA), formerly the SADS Foundation, is a nonprofit patient advocacy organization dedicated to empowering individuals and families living with inherited arrhythmias to live fully and thrive beyond their diagnosis. Founded in 1991, FIA serves a global community through expert-backed patient empowerment and family support, medical education for clinicians, community-building, research advancement, and life-saving advocacy and awareness efforts. Guided by the world's leading experts in inherited arrhythmias and committed to accelerating medical advances, FIA offers families hope for a life unlimited by their inherited heart rhythm condition.