Aortic Dissection Awareness:
What Works, What Doesn't, and What We Need Most

Awareness of aortic dissection has never been higher, but to improve outcomes for patients and their families, we need to utilize existing guidelines and knowledge to find people at risk before dissection.

By Ellen Hostetler and Meredith Ford O'Neal

When actor and comedian John Ritter died of an aortic dissection (AD) in 2003, he put a face to a condition that many people had never heard of. Many had grown up watching him on television, welcoming him into their home week after week on shows like *Three's Company* and *8 Simple Rules*. In the 23 years since his death, other high-profile cases have continued to renew awareness and interest in AD, including the survival of Richie Faulkner, lead guitarist of Judas Priest, who had an AD while onstage. In July 2026, the death of Senator Lindsey Graham again brought AD into the national conversation, leading to front-page coverage in traditional news outlets like *The New York Times* as well as widespread discussion on social media. Physicians and researchers who focus on AD suddenly found that their work was of more interest to friends and family than ever.

On September 19, 2016, Swedish AD survivor Timo Söderlund, along with a group of international survivors, established Aortic Dissection Awareness Day. Over the past 10 years, this campaign has grown into a coordinated movement spanning an entire week, involving nonprofits, patients, clinicians, and researchers. Aortic Dissection Awareness Week now brings attention to AD through social and traditional media, local proclamations and patient meetups, conferences, and educational webinars.

In 2026, eight North American nonprofits focused on AD and relevant high-risk conditions came together to share the message of STAT:

- **S**uspect sudden, severe tearing chest or back pain
- **T**ime matters
- **A**ortic imaging saves lives
- **T**alk about it, because dissection runs in families

This year, Aortic Dissection Awareness Week posts from The John Ritter Foundation for Aortic Health (JRF) reached more than 1.5 million combined views on Facebook and Instagram alone. However, awareness is only useful if it changes patient outcomes. We need to determine whether these awareness efforts are helping people get diagnosed sooner, leading the right patients to get preventive surgery, and ultimately reducing deaths. Views and impressions alone cannot answer those questions.

WHAT WORKS

Surgical outcomes are one area where we can see meaningful progress in AD care. A report from the International Registry of Acute Aortic Dissection published in 2022 found a mortality rate of 0.09% per hour among acute type A AD (TAAD) patients with planned or completed surgery, substantially lower than the frequently cited historical estimate of 1% to 2% per hour.[1]

Patients and families are also increasingly aware of the value of multidisciplinary aortic centers and, when able, may travel to receive care at centers with specialized expertise. The adoption of endovascular techniques has also expanded treatment options for selected patients with thoracic aortic disease.

Through patient groups and peer support programs, patients are also advocating for care that addresses more than immediate recovery after surgery. They are normalizing mental health recovery needs, sharing the value of cardiac rehab, and highlighting the lack of evidence around exercise and physical activity.

WHAT DOESN'T WORK

Although patient groups amplify patient voices and can help identify important unmet needs, greater awareness of aortic disease may also have unintended consequences. Individuals who perceive themselves to be at risk may seek out patient communities, where exposure to frightening patient experiences can heighten anxiety and perceived illness threat. Importantly, aortic size does not reliably predict perceived illness threat, and a recent study found that smaller aneurysms were not consistently associated with less anxiety or distress.[2] Although awareness can encourage appropriate evaluation and risk management, it may also increase fear among individuals whose actual risk is relatively low.

Our website data show that one of the most common search terms that generates visitors is: "How many people die of an aortic dissection?" Although studies examining incidence in specific populations exist, deaths outside of the hospital remain difficult to quantify. Population-based studies suggest that a substantial proportion of individuals with acute TAAD die outside of the hospital.[3,4] Many of these individuals do not undergo an autopsy, meaning the true incidence of AD is likely underestimated. For example, John Ritter's own father, Tex, died suddenly after chest pain. His death certificate attributed the cause to myocardial infarction, although no diagnosis was made in a hospital and no autopsy was performed. It is plausible that an AD could have been the true cause, with the death attributed to the more common diagnosis of myocardial infarction.

We were reminded how many families first learn about AD after a loss during Aortic Dissection Awareness Week, when a JRF social media post about grief after AD brought comments from people remembering children, siblings, parents, and partners. The Ritter family's willingness to be open about grief and loss due to AD has made the JRF a natural home for families that share this grief. These families also remind us that there is no single system in place to connect unexpected deaths from aortic disease with genetic evaluation and screening for surviving relatives. Whether a family is offered this opportunity may depend on whether the medical examiner or coroner happens to have the knowledge, connections, and time to pursue it. Many medical examiner offices also have limited resources for postmortem genetic testing, and insurance coverage for testing after death is often unavailable.

This is one area where current awareness efforts fall short. Campaigns aimed at the public and emergency clinicians do little for families after a sudden death, a common outcome. Forensic pathologists need low-barrier, pragmatic workflows for connecting surviving family members with genetic counseling, testing, and aortic screening. The JRF is currently working with forensic pathologists and others involved in this process to better understand what is needed and how these pathways can be built. Increasing awareness among these professionals is an important first step, but ultimately, these efforts need to be paired with a way to connect families to the care and testing they may need.

Diagnosis of acute AD in the emergency department continues to be a challenge due to the overlap of major symptoms such as chest pain with other conditions, the relative rarity of the disease, and systemic issues. Much of the global awareness efforts have focused on helping emergency medicine clinicians recognize the symptoms. The JRF is working with and investing in the American College of Emergency Physicians and emergency medicine researchers to develop practical ways to improve recognition and diagnosis of AD. Solutions cannot depend on simply asking doctors and other health care professionals to be more aware. They need to be practical in the emergency department, fit into existing systems, and be developed with the clinicians who will actually use them.

Another part of the challenge is increasing awareness that AD can occur in patients who are outside of the typical risk profile. Thoracic AD is more common in older men, particularly those with hypertension.[5] As a result, patients who fall outside of that profile may be less likely to have AD considered as a diagnosis. Although awareness of Marfan syndrome among clinicians and the public has increased, knowledge of other genetic aortopathies, especially those without obvious syndromic features, is still lacking. Awareness efforts should emphasize that age, sex, prior health status, and the absence of syndromic features are not reasons to dismiss symptoms, family history, or the value of genetic evaluation.

WHAT WE NEED MOST

As diagnosis, surgical techniques, and postoperative care continue to improve, preventing AD by identifying individuals at high risk prior to an event remains a major opportunity to reduce mortality and morbidity. Genetic discovery, the use of machine learning to identify risk in medical records, and other advances are promising, but we believe some of what is needed most right now can be done with the technology, evidence, and guidelines we already have.

We propose two pathways with the same goal: identifying risk before dissection. For individuals with genetic aortopathies, this means recognizing genetic risk and identifying at-risk family members before an event occurs. For patients with so-called "sporadic" disease,

who make up the majority of patients with AD, recognizing the significance of an incidental thoracic aortic aneurysm finding and ensuring appropriate follow-up can provide another opportunity to identify risk before AD.

Pathway 1: Genetic Risk

The 2022 American College of Cardiology/American Heart Association guideline for the diagnosis and management of aortic disease contains several class 1 recommendations for family screening and genetic evaluation.[6] Despite clear guidance, we continue to hear from patients who were not told or did not leave with an understanding that their condition could be heritable. Just as common, family members who try to obtain screening via aortic imaging are told they do not need it, that it would not be covered by insurance, or, in some cases, given an ultrasound of the abdominal aorta only.

Raising awareness of these recommendations among health care professionals as well as in patients and families can help bring them into practice if paired with supportive systems and navigation. In genetics, there is a saying that "the cheapest genetic test is taking a good family history."

The surgeon has a particularly important role in preventing AD in those with genetic risk. A recommendation from the surgeon to have family members screened can carry more weight than a pamphlet or social media post. These are the people who have just cared for a patient through a life-threatening event, and their recommendation can make the importance of family screening clear. For vascular surgeons who follow patients with residual descending aortic disease after TAAD or type B AD, there is also an opportunity to reinforce this message over time.

Awareness of the guideline recommendations must include recognition of nonsyndromic genetic aortopathies, such as *ACTA2*-associated heritable thoracic aortic disease. These conditions may not be recognized as hereditary because there are no outward features to suggest a genetic cause (eg, tall stature, hypermobility, facial characteristics). Families may experience multiple dissections or deaths before the underlying genetic risk is recognized. Patients with nonsyndromic genetic aortopathies also resort to describing their condition as "like Marfan" to medical providers. This highlights the need to expand the clinical picture of genetic aortopathies beyond the syndromes that are most familiar, such as Marfan syndrome and Loeys-Dietz syndrome.

Pathway 2: "Sporadic" Disease

The majority of AD patients will not have a family history of aortic disease. Because there are no screening recommendations for the general public without known risk factors, individuals with "sporadic" aortic disease are currently identified in advance of an AD only when aortic enlargement or aneurysm is found incidentally. We have seen an increasing number of individuals reach out to JRF after a thoracic aortic aneurysm was identified incidentally on a coronary artery calcium (CAC) scan. Although diameter is an imperfect predictor of AD risk, it is certainly a variable that should be incorporated when available. As CAC scans become more common, awareness of the meaning of an aortic finding could turn these scans into opportunities to identify people at high risk before AD.

Consistent measurement of the aorta when it is visualized on these scans, reporting of aortic measurements, and guideline-directed follow-up, including continued surveillance and additional imaging when appropriate, are needed to make the most of these opportunities for early diagnosis.

Implementing the Pathways

We believe these two pathways matter and can be integrated into care without waiting for new discoveries or technology. Clinicians should be aware of the importance of asking about family history in every dissection case, and systems should ensure that the class 1 guideline recommendation for screening at-risk relatives is shared. Recognizing that nonsyndromic genetic aortopathies are not rare could also help identify at-risk family members before they experience an AD. Screening should not be restricted to those who fit a physical phenotype. As partners in their care, patients should have access to information from reputable sources and feel empowered to ask questions and advocate for appropriate screening and follow-up.

MEASURING WHAT MATTERS

Awareness should be judged by whether it changes recognition, action, and outcomes. Meaningful measures could include the proportion of patients whose at-risk relatives complete aortic imaging, how often incidental aortic findings are reported with measurements and acted on with appropriate follow-up, and how often AD deaths lead to postmortem genetic testing and aortic imaging for at-risk relatives.

The goal is not simply to make AD better known but to ensure that existing knowledge and clinical guidelines are put into practice to improve patient outcomes. ■

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1. Harris KM, Nienaber CA, Peterson MD, et al. Early mortality in type A acute aortic dissection: insights from the International Registry of Acute Aortic Dissection. JAMA Cardiol. 2022;7:1009–1015. doi: 10.1001/jamacardio.2022.2718
2. Patel E, Sargeant MM, Jordan E, et al. Bigger isn't always scarier: aneurysm size and illness perception in thoracic aortic aneurysm patients undergoing surveillance. Vascular Medicine. Published online July 6, 2026. doi: 10.1177/1358863X261442903
3. Howard DP, Banerjee A, Fairhead JF, et al. Population-based study of incidence and outcome of acute aortic dissection and premorbid risk factor control: 10-year results from the Oxford Vascular Study. Circulation. 2013;127:2031–2037. doi: 10.1161/CIRCULATIONAHA.112.000483
4. Yamaguchi T, Nakai M, Yano T, et al. Population-based incidence and outcomes of acute aortic dissection in Japan. Eur Heart J Acute Cardiovasc Care. 2021;10:701–709. doi: 10.1093/ehjacc/zuab031
5. Pape L, Awais M, Woznicki EM, et al. Presentation, diagnosis, and outcomes of acute aortic dissection: 17-year trends from the International Registry of Acute Aortic Dissection. J Am Coll Cardiol. 2015;66:350–358. doi: 10.1016/j.jacc.2015.05.029
6. Isselbacher EM, Preventza O, Black JH 3rd, et al. 2022 ACC/AHA guideline for the diagnosis and management of aortic disease: a report of the American Heart Association/American College of Cardiology Joint Committee on Clinical Practice Guidelines. Circulation. 2022;146:e334–e482. doi:10.1161/CIR.0000000000001106

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