Initiatives to Improve Awareness of Aortic Dissection

Advocates with Aortic Hope/Think Aorta, The John Ritter Foundation for Aortic Health, and The Aortic Dissection Collaborative for Patient-Centered Research discuss how they are raising awareness of aortic dissection through research and education.

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To begin, tell us about your organization. What is your organization's mission?

Ms. Andersen and Dr. Youdelman: Think Aorta US (TAUS) and Aortic Hope are two very different organizations, with TAUS a preactive organization and Aortic Hope a reactive organization. TAUS promotes the understanding of aortic disease to the public and health care workers. TAUS conducts multimedia educational programs and public service campaigns to bring attention to the importance of knowing your family medical history and the impact it has on individual health. TAUS is endorsed by the Society of Thoracic Surgeons (STS), Society for Vascular Surgery (SVS), and Aortic Hope.

Aortic Hope aims to spread hope, create awareness, and provide support to patients and their caregivers during the recovery and management of aortic disease. As physicians are diagnosing aortic disease patients, Aortic Hope provides the necessary support and resources for success as patients deal with the complex recovery from aortic dissection (AD), a new diagnosis, or aortic disease in general.

Collaboratively, the two organizations work with the community, clinicians, and patients/families alike through the "Think Aorta, Think Family" campaign, which emphasizes the sharing of experiences and the importance of knowing the family history. Patients and their families help distribute awareness posters to local emergency departments (EDs) and physician offices.

Ms. Hostetler: The John Ritter Foundation (JRF) for Aortic Health was established in 2003 after the tragic death of John Ritter—beloved actor, husband, father, and friend—due to an AD. Our mission is to raise awareness of thoracic aortic aneurysm and dissection through research, education, and advocacy. We aim to prevent death and disability resulting from AD through funding research and engaging both clinicians and patients.

Mr. Howitt: The Aortic Dissection Collaborative for Patient-Centered Research aims to improve quality of life (QOL) for people impacted by AD by prioritizing the voice of the patient in medical research and treatment protocols. The collaborative has assembled a network of patients, doctors, researchers, industry stakeholders, and advocacy groups to gather feedback on what patients see as the biggest gaps in treatment of (and living with) ADs. By engaging patients through surveys, one-on-one interviews, and online community forums, the collaborative has identified what patients believe should be the top priorities for ongoing research and what shortcomings patients typically experience in their own treatment. Typical clinical trials tend to prioritize medical outcomes from a doctor's perspective as criteria for success while shortchanging the impacts on QOL, emotional health, and other adjacent health issues. The collaborative is seeking to elevate these patient concerns.

What is known about the overall level of public awareness of aortic diseases, including AD?

Ms. Hostetler: We believe that AD is underrecognized by both the general public and the medical community. A common refrain we hear from patients and families is that they had never heard of this condition prior to diagnosis and that they feel there is little that can be done to prevent poor outcomes. Although John Ritter's death from an AD, the establishment of the JRF, and work of partner organizations have raised the profile of this condition, sustained efforts—particularly in high-risk populations—are needed. For instance, despite clear recommendations in the current American Heart Association/American College of Cardiology (AHA/ACC) guidelines for screening of at-risk relatives, patients are often unaware of the potential heritable nature of aortic disease. We believe this is a key area in which partnering with surgeons creates a unique opportunity to save lives.

Ms. Andersen and Dr. Youdelman: There has been an increased awareness of aortic disease over the last several years because people are more willing to discuss their medical issues and family medical history. However, the complexity associated with aortic disease is at its infancy in terms of the general public understanding the implications for families if a single person is diagnosed with aortic disease. This limitation is largely due to the rare discussions about aortic disease in medical school because it was believed to be sporadic and rare, as family members who had sudden death were labeled as having had a "massive heart attack" when we now believe many were ADs or aortic ruptures.

The familial nature of aortic disease is now known, and the associated genetics are being defined. The majority of physicians and health care workers will have little exposure to aortic disease, but it is more common than previously thought.

In studies in multiethnic communities, the incidence of aortic aneurysms may be as high as 10% (unpublished data), but the incidence of AD is unknown as many deaths are not accurately defined. Many patients with ADs will die and be reported as having unexplained sudden death, massive heart attack, and unknown death. The value of autopsies has been understated in recent years, but for any familial/genetic diseases, autopsies can be lifesaving for the next generation.

What are the goals of raising awareness (ie, detection, prevention of progression, finding providers, tips for healthier living with the condition)?

Ms. Andersen and Dr. Youdelman: The goal is to identify patients and families who are at risk for aortic disease by promoting the Think Aorta, Think Family initiative and increase the number of safer elective operations to decrease the incidence of ADs. Overall, the goal is to detect aortic disease and high-risk families, increase elective surgery, and see a decrease in emergency surgery.

Ms. Hostetler: We envision a world where early detection of aortic disease, along with proper management, can prevent most ADs and the associated tragic deaths and chronic disabilities. This vision guides our foundation's prioritization of funding research to identify the genetic factors responsible for thoracic aortic disease. Simultaneously, we recognize that we need to facilitate better care for patients now to prevent disease progression and help individuals live full and long lives with this diagnosis. We advocate for a collaborative model where physicians with expertise in aortic disease, other medical providers, patients, and their loved ones work together as a team. Although not every medical provider can be an expert in aortic disease, we know that access to specialists who diagnose and treat a high volume of aortic patients can improve outcomes. A major part of our patient-facing work is to facilitate these connections. We hope that by engaging patients, we can empower them to take an active role in their care.

What have you found to be the most successful methods for raising public awareness of AD?

Ms. Andersen and Dr. Youdelman: The most successful method has been twofold: (1) patients and their families teaching their physicians about the familial nature of aortic disease and getting themselves evaluated, and (2) sharing the message to the people caring for those already identified as having aortic disease. Posters were sent to every ED in the country twice, and although we have no special metric to know how successful this campaign is, we do get a response at the medical conferences that the awareness campaign and the importance of bringing it to the ED is known by others.

Ms. Hostetler: Media coverage, both locally and nationally, has brought the term "aortic dissection" into the homes of millions. We are fortunate to have individuals with large public profiles who have helped share our message widely. Equally important are our partnerships with health care organizations and medical experts who have extended our reach by hosting us for educational events, offering speaking opportunities, and providing free screenings.

What can physicians and team members involved in AD care do to help improve public awareness in their communities?

Ms. Hostetler: First, we encourage you to refer patients and their family members to our foundation! We offer free resources, including the book *Life With Aortic Disease: Caring for Your Mental Health*, which addresses an important unmet need in this population, as well as a peer-support program, an ongoing webinar series with experts, and local fundraising and community-building efforts.

Second, as physicians and medical providers involved in the care of patients with AD, you play a vital role in encouraging patients to inform their relatives about their potential risk and need for aortic screening. Given the trust patients place in their surgeons, this is an immediate opportunity to significantly impact patient outcomes by bringing awareness of screening recommendations.

Ms. Andersen and Dr. Youdelman: Providing the resources that Aortic Hope offers, such as the Think Aorta, Think Family initiative, ensures that patients and caregivers have a place to feel supported and validated. Patients tend to want to become involved in awareness once they understand more about the disease. Participation varies from online sharing of materials, promoting events, fundraising, and active volunteerism.

The involvement of physicians and other health care workers in educational campaigns like TAUS and Aortic Hope provides an opportunity to learn from patients, which in turn allows them to provide better care. This can increase career satisfaction as the effects of these efforts on the families are appreciated.

Ms. Hostetler, the JRF website provides guidelines for patients living with aortic disease, including exercise and activity recommendations. How did the JRF develop these, and how do they help patients learn to live and thrive with their condition?

Ms. Hostetler: These guidelines were developed with input of our professional advisory board in response to a need we observed in patients and their caregivers postdissection. Myths and misunderstandings about the safety of exercise and activity after AD are persistent and have led many patients to adopt a sedentary lifestyle out of fear, including limiting exercise, sexual activity, and employment. Although there are certain types of exercise and activity that may not be recommended depending on diagnosis and health status, we believe that living an active and fulfilling life after AD should be everyone's goal. We recently funded the first clinical trial of exercise in individuals who have survived AD to address this important topic.

Ms. Andersen and Dr. Youdelman, Aortic Hope and TAUS have collaborated to produce educational materials via their SVS/STS-endorsed "Aortic Dissection: The Patient Guide." What are some of the essentials for effective patient education? What did the collaboration with the SVS and STS comprise?

Ms. Andersen and Dr. Youdelman: It is essential for patients to know that they are not alone. Hypertension management is critical, as well as communicating with family members about their medical issues because it isn't just the aorta. High blood pressure, diabetes, stroke, cancer, and aortic disease run in families. It was essential to have this guide written by patients and clinically reviewed by experts. As a patient, reading and learning about aortic disease as told by patients creates a sense of understanding and belonging. There is a degree of vulnerability when facing this disease that only another patient can relate to. This easy-to-understand guide has been deemed the guide that patients wish they received after their AD because they firmly believe it would have made recovery easier.

The collaboration with SVS/STS comprises a unified message for patients and families regarding medical management, surgical management, and family surveillance with cascade screening, and it includes a vetting validation, confirming the unified approach to the medical and surgical care of the patients with aortic disease.

Mr. Howitt, you've coauthored a number of peer-reviewed papers with the Aortic Dissection Collaborative. What role can patients play in scientific research and evidence generation?

Mr. Howitt: ADs are thankfully not as prevalent as other diseases such as cancer or heart disease. Thus, real-life experiences of AD patients and our medical data are actually much more valuable than most of us realize. If patients have the opportunity to participate in clinical trials or allow their medical data to be used anonymously, they can potentially make a huge impact on the treatment of countless future AD patients. In addition, providing a DNA sample (typically a spit test) to organizations like the JRF will aid the effort to better understand the genetic causes of ADs.

Ms. Andersen and Dr. Youdelman, the Think Aorta, Think Family campaign encourages family members of patients with aortic disease to look into being evaluated. Can you tell us more about this component of the TAUS program?

Ms. Andersen and Dr. Youdelman: Implementing the Think Aorta, Think Family initiative is an easy and effective way to have patients and caregivers involved in creating public awareness of aortic disease. Sharing success stories with TAUS, which explains how these sometimes-awkward conversations about medical history have unfolded, instills confidence in others to have those same tough conversations among themselves and with their medical team.

Ms. Hostetler, can you tell us about the JRF's Aorta Advocate peer support program and how it works?

Ms. Hostetler: We developed our Aorta Advocate program in response to an overwhelming unmet need. We were receiving dozens of calls and emails each week from individuals across the country (and sometimes the world) who were struggling with life after diagnosis, following an AD, being a caregiver, or grieving the loss of a loved one to AD. Additionally, we observed and experienced well-intentioned misinformation being widely shared on social media and other informal channels where patients engaged. We aimed to create a program that would serve both needs: to offer an empathetic ear from someone who can relate to their experience and to empower patients and family members to advocate for themselves while navigating reputable resources. Today, we have 40 volunteers with diverse, lived experience with aortic disease who underwent an extensive 3-day training and are ready to support patients. They do not provide medical advice and are not a substitute for mental health care. The program is free and available to individuals with or at risk for thoracic aortic aneurysm and dissection, their caregivers, and anyone who has lost a loved one to these conditions. Participants are matched with a volunteer based on their needs and can connect by email, phone, or text depending on their preference. We are proud to fund a program that provides peer support in a structured and responsible way.

Mr. Howitt, what do you see as the essential research needs for the AD patient population?

Mr. Howitt: In our surveys and interviews with the AD community, a number of key themes emerge. The biggest issue is a consistent lack of education regarding AD across the medical community. ED physicians, first responders, and primary care physicians seem to have a remarkably inconsistent understanding of how to diagnose and then treat AD. We've heard numerous stories of what we described as "unnecessary drama" associated with patients' initial diagnosis of their ADs either through miscommunication or outright misdiagnosis, as I experienced firsthand. Efforts to better educate the broader medical community is clearly a high priority with patients.

Continued research into the genetic causes of ADs was another key theme. Patients feel the need to understand what happened to them and why. There's also a sense of belonging to a broader community (eg, Marfan syndrome) when a cause can be identified. In addition, a genetic explanation allows families to better understand the extent of the hereditary risk through genetic testing. Surgical techniques, medications, exercise restrictions, and mental/emotional health impacts were other key themes that emerged as key areas for future emphasis.

Ms. Hostetler, the JRF website includes summaries and links to information regarding a series of ongoing studies, including The John Ritter Research Program in Aortic and Vascular Diseases (JRRP), which aims to explore genetic and environmental risk factors affecting aortic disease. Can you tell us more about the research arm of the JRF and its progress to date?

Ms. Hostetler: The JRRP is a collaboration between The University of Texas Health Science Center at Houston (UTHealth) and JRF that began in 2012 and is led by Dr. Dianna Milewicz, an internationally recognized expert in the genetics of aortic and vascular diseases. Her lab has identified 18 genes for thoracic aortic aneurysm and dissection. Funding from the JRF has significantly supported publications to identify genes, define gene-specific management, and recognize molecular triggers for dissections. This research provided data for the 2022 AHA/ACC guidelines for aortic disease, guiding precise management to prevent dissection and improve patient outcomes.

To illustrate the impact of this research, we can point to our own CEO, Meredith O'Neal, who is the fifth person to experience AD in four generations of her family. The disease-causing variant was identified by the JRRP in 2022. Although the genetic cause of aortic disease in the Ritter family has not yet been identified, they are participants in the JRRP and eagerly await the day they and all families affected by heritable aortic disease receive an answer.

Ms. Andersen and Dr. Youdelman, Aortic Hope has a YouTube channel that includes live question-and-answer events with clinicians, survivor stories, and a cooking program. What can you share with us about the Aortic Hope TV YouTube channel and its goals?

Ms. Andersen and Dr. Youdelman: Aortic Hope has a very active YouTube channel that features live question-and-answer events with a variety of clinicians taking questions from the public, survivors sharing their stories and interacting with the community, and weekly reviews of accurate educational blog posts. We have created a community by survivors, for survivors and their caregivers. This community has a lot of variety including the Aortic Kitchen, Qigong, and the Aortic Artist.

JRF has anchored several of its key awareness-generating events around marathons, including the New York Marathon and Disneyland Half Marathon. How does engagement with larger events such as these facilitate generating awareness as well as fundraising?

Ms. Hostetler: The JRF has been a proud charity partner of the TCS New York City Marathon since 2012. Lovingly called Team Ritter, this group of runners raises crucial funds and awareness for our mission. Since then, we have expanded Team Ritter to include other active events throughout the country. Active events such as marathons are a key strategy for the JRF to raise awareness. They allow us to engage our supporters with the mission in a deeper way through a year-long journey together. Runners are typically personally connected to the cause, knowing and loving someone who has personally been affected by AD. Running in honor or memory of a loved one, or in some cases, for themselves, gives higher meaning to the 26.2 miles. Passion also inspires these runners to raise crucial funds for our mission, with NYC Team Ritter raising almost $1,000,000 since 2012. It culminates in runners completing a marathon, their Team Ritter shirts visible to millions of spectators. Over time, we hope Team Ritter becomes a movement, and we will have teams running races throughout the country, raising awareness and funds for JRF, and moving the needle on AD.

Mr. Howitt, what is your advice to other AD patients who are interested in contributing to research or awareness initiatives?

Mr. Howitt: There are a number of community forums dedicated to the needs of people impacted by ADs. Some are patient-driven (eg, Aortic Hope) and others are managed by medical professionals (eg, JRF, Genetic Aortic Diseases Association Canada), but they all share a common goal of bringing people together to improve the long-term outcomes for AD patients. Patients have the ability to engage in any of these they are interested in. Almost all of these forums run periodic online sessions to either educate patients and doctors or simply provide a place for patients and caregivers to come together to exchange experiences. The latest research initiatives are often discussed and offer the potential for patient involvement. My advice is to get online and engage in as many of these sessions as is practical. In addition, online affinity groups for AD patients exist on social media platforms such as LinkedIn, Instagram, and Facebook. I have found it to be remarkably healthy to be able to interact with other AD patients and know that there are other people out there who have had similar experiences to what I went through. ■

Disclosures
Ms. Andersen: None.
Dr. Youdelman: None.
Ms. Hostetler: None.
Mr. Howitt: None.