

Sharing Your Aortic Story: A Guide for the Community

You can play an important role in raising awareness about thoracic aortic aneurysm and dissection! Your story is a powerful tool for bringing attention to this often-overlooked condition and educating medical professionals, patients, and the wider public.

Where to share your story:

The most effective place for patients and families to advocate is often in their own community. We offer some suggestions here but encourage you to get creative!

- Hospitals and clinics: Your medical care team may have opportunities for patient representatives to speak at their internal forums.
- Religious or spiritual gatherings, community groups, social clubs.
- Fundraisers are often covered by local news stations. Please check out our [fundraising toolkit](#) if you are interested in hosting an event.
- Workplace “lunch and learns” or similar educational programs.
- School projects: whether you are in high school or an advanced learner, focusing a school assignment or project on aortic disease can be a great way to educate others.

Note: The John Ritter Foundation for Aortic Health does not currently have speaking opportunities for patients or community members.

“I talk to healthcare providers differently than I do with my friends on social media.”

Tips for Effective Storytelling:

Know your audience: Consider who you are sharing your story with and tailor your narrative to resonate with their experience and knowledge.

Be selective: Choose key moments or events in your story that best illustrate your aortic journey. Too many details may overwhelm your audience. Attention spans are short – prioritizing the most important parts of your story will make it more effective.

Think about your motivation: What impact do you want your story to have?

“I find doctors are surprised when I tell them I had a dissection at age 35, sometimes they think it happens only to older people.”

- **Awareness:** Many people do not know where the aorta is and have never heard of an aortic dissection. Your story can contribute to raising awareness about this condition, risk factors, and the importance of family history.
- **Education:** The public and even medical providers may have misconceptions about thoracic aortic disease. Your story can help dispel myths.
- **Community Support:** Your story can empower others to be active participants in their healthcare. By sharing your journey, you encourage others to ask questions, and actively engage in decision-making processes.

Tips for Sharing on Social Media:

- **Be authentic:** Share your lived experiences, challenges, and victories.
- **Make it visual:** Use photos or short videos whenever possible to make your posts engaging.
- **Privacy:** Remember that once shared, your story becomes public. Be sure you’re comfortable with the information you choose to disclose. Consider the potential impact on others, **especially minors or anyone who can’t consent.**
- **Acknowledge uniqueness:** Recognize that everyone’s aortic journey is different. Be mindful and respectful of others’ experiences, particularly if they choose to engage publicly.
- **Get the details right:** If you share any facts about thoracic aortic aneurysm and dissection, be sure they come from a trustworthy, reputable source. Our website, johnritterfoundation.org is a great place to start!