



Educating Local First Responders about VEDS (Vascular Ehlers-Danlos syndrome)

VEDS (Vascular Ehlers-Danlos Syndrome) is a rare connective tissue disorder that affects the blood vessels, organs, and skin. Due to the potential for life-threatening complications in emergencies, it's essential for first responders to understand the condition.

Key Resource: [First Responders Quick Guide](#)

Getting on the Agenda:

Identify the Right Contacts: Reach out to the training coordinators or public education officers of local fire, EMS, and paramedic units.

Prepare a Brief Introduction: Clearly state your purpose, the importance of understanding VEDS, and how this awareness can save lives.

Offer to Host a Training Session: Propose a specific date, time, and location for an informational session.

Provide Credible References: Offer information from reputable sources (e.g., The VEDS Movement or related health organizations) to underscore the importance of this educational initiative for effective emergency response.

Join Local Advocacy Groups: Connect with local health advocacy organizations that may have existing relationships with first responders.

Follow Up: After your initial contact, follow up in a week or two to show you're genuinely interested in educating them.

What First Responders Should Know:

Recognizing VEDS: Individuals may carry a medical alert bracelet or card indicating their condition. They might also have thin, translucent skin and visible veins, especially on the chest and abdomen. Facial characteristics may be subtle but if you demonstrate some of these characteristics it may be helpful to point them out.

Potential Emergencies:

- Sudden and severe pain: could indicate arterial or organ rupture.
- Signs of stroke: as individuals with VEDS can experience strokes at younger ages.
- Unexplained bruises: indicative of potential internal bleeding.

- Breathing difficulties: could be due to a lung collapse or other complications.

Handling VEDS Patients:

- **Gentle Handling:** Their skin and vessels are fragile; use caution.
- **Avoid Invasive Procedures:** Only if absolutely necessary, as they can lead to complications.
- **Quick Transport:** Time is of the essence, especially if arterial or organ rupture is suspected.
- **Immediate Medical History:** Ask if they've had surgeries or known aneurysms, as this impacts treatment decisions.

Effective Communication:

- **Calm and Reassurance:** Stress can exacerbate symptoms. Provide calm assurance to patients.
- **Listen Actively:** Understand any specific concerns or symptoms they mention.

Tips for Educating First Responders:

- **Use Real-Life Scenarios:** Share personal stories or scenarios where understanding VEDS made a difference in outcomes.
- **Visual Aids:** Use infographics, videos, or slide presentations. They can make complex medical topics easier to grasp. (RR - check to see if we have a presentation developed they can use when presenting to first responders)
- **Interactive Learning:** Consider hands-on demonstrations, role-playing, or quizzes to engage your audience.
- **Provide Printed Material:** The VEDS First Responder Quick Guide or VEDS Emergency Alert Card they can carry or have in their vehicles can be invaluable.
- **Build a Relationship:** Don't make it a one-time session. Regularly update them with new information and offer refresher courses.

By taking a proactive approach in educating our first responders about VEDS, we can ensure that patients receive the best possible care in emergencies.