



TELLING YOUR STORY

Here are some tips for constructing your personal bleeding disorders story for talking with a Legislator, Legislative staff, or others who you need to influence.

- Before you start – take a moment to think about what you hope to accomplish by telling your story.
 - Are you seeking to raise awareness? Do you want them to make a decision? Support a bill? This will guide what you include in your story.
- Remember to be brief. Ask yourself, “Is everything I am about to say necessary to achieve my goal?”
- Be memorable. Help the person who is listening to your story to SEE your experience by being descriptive and giving an example.
- Start by introducing yourself – your name, where you live, and your connection to bleeding disorders.
 - For example: My name is Lynne Kinst. I live in Rocklin, California and my dad was born with severe Hemophilia B, which is Factor 9 deficiency. I am also a carrier of the hemophilia gene and have mild Hemophilia B.
- Ask if they know anything about bleeding disorders or if they have heard about hemophilia before.
- Most likely they won't be very familiar with your bleeding disorder, so take a moment to explain.
 - For example: People with hemophilia don't make one of the proteins their blood needs to clot properly. To stop or prevent bleeds, I must infuse expensive medication three times a week. The medication is called clotting factor. If I get a bleed, I may have to infuse more often and on average, my factor replacement medication costs \$300,000 per year.
- Connect your story to one of the issues we are discussing – i.e., the importance of access to health care which has helped you stay healthy.
- Don't forget – the best person to tell your story is YOU!