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## 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.

1. 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.
2. Remember to be brief. Ask yourself, “Is everything I am about to say necessary to achieve my goal?”
3. Be memorable. Help the person who is listening to your story to SEE your experience by being descriptive and giving an example.
4. 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.*
5. Ask if they know anything about bleeding disorders? For example, *have you heard of hemophilia before?*
6. 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 in order to clot properly. In order 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.*
7. Many stories talk about joint pain and swelling in your joints – we all know this is a common problem due to hemophilia or VWD causing bleeding into joints, but your listener may not understand this. If this is part of your story, take a moment to explain that joint bleeds are a common problem for people with bleeding disorders and explain the complications and life-long problems this causes without proper treatment. For example, *A common issue for people with bleeding disorders is painful bleeds into their joints. I can remember my dad often getting bleeds in his shoulder, ankle, elbows and knees. When I was in high school he had knee replacement surgery because frequent bleeds caused so much damage to his knee that he didn’t have any cartilage left.*
8. 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.
9. Don’t forget – the best person to tell your story is YOU!