



# Learning and Overcoming

Jacey talks about her life with von Willebrand Disease, her worst night ever and what she wants the newly diagnosed to remember.

Jacey, (above, left) has remained active despite her von Willebrand Disease diagnosis. Among her extra curricular activities, playing softball at Rancho High School.

There's a lot of learning involved in order to live with an inherited bleeding disorder.

You have to learn about the disorder itself, learn how to self-infuse, learning personal limits and what can and cannot be done on a daily basis. Jacey was forced to learn those things since she was diagnosed at age eight by her oncologist, who was treating her for leukemia at the time.

It would be several years later when Jacey, living with von Willebrand disease (vWD), learned the hard way that if her blood pressure becomes too low, it turns into a very serious situation.

When Jacey was a junior in high school, she was “having a lot of clotting issues in general, joint bleeds, menstruation, bruising like no other.” These things on top of stress from school, and infusions really got to her. She was in a lot of pain every day for about a week, and one night, “in the middle of the night, I woke up in such a bad state of being. I felt weak and dizzy and oriented. I got out of bed and walked down the hallway, and after that, everything went black.”

Jacey woke up in the emergency room because her blood pressure had become too low, which caused her to lose consciousness. She said, "It was one of the hardest days of my life, because that day my bleeding disorder beat me."



After this incident, Jacey sought help from the Hemophilia Treatment Center of Las Vegas where she was able to find "a way to manage the times when my blood pressure does in fact drop. Everything since then has been getting better, but that was by far my worst day as a person with an inherited bleeding disorder."

Since then, Jacey has learned ways to manage her vWD. She plays softball and golf by making sure she has medicine on hand and she properly infuses beforehand. Quitting was never an option. In fact, she played softball before her diagnosis so "everyone understood that there was nothing that would make me give it up." Her strong will helped her be "determined that vWD would not affect my daily life as much as possible."

After the worst possible day of living with an inherited bleeding disorder and everything she has learned, Jacey has advice for younger kids who are learning to live with an inherited bleeding disorder: "My advice would be to not let the disorder beat you. This is something you will end up living with for the rest of your life, so learn to love it. Take part in the activities and seminars you are invited to, get involved and learn how you can help other people that are in the same position that you once were. Embrace it and face it head on. If you don't cower, your disorder doesn't win and that is the overall goal when managing a chronic illness."



The Nevada Chapter of the National Hemophilia Foundation offers a number of support groups, including groups for families of newly diagnosed children. For additional information on support groups or any other services and benefits provided by NHF Nevada, please call (702) 564-4368 or email Anne at [amcguire@hemophilia.org](mailto:amcguire@hemophilia.org).