

## **Daniela Delgado Speech**

Thank you so much to National Hemophilia Foundation for the opportunity to speak this evening. My name is Daniela Delgado. I am 9 years old. I am in 4th grade. And I am from Stamford, CT.

At the age of 4, I founded a community program called Daniela's Little Wish. I bake, decorate and deliver birthday cakes at no cost to kids living with life threatening illnesses, a lot of them live with rare conditions like hemophilia, von Willebrand disease and other types of bleeding disorders.

I have seen so many kids from ages 1 to 21 years old that have had very hard times in their lives. I have seen their frustration, desperation, pain and death but I have also seen love, support, help, and hope.

At my age, I know the difference between doing well and doing good and the necessity of helping others. My life in this world is to do things for others and that is why I have Daniela's Little Wish because no one deserves to be sick – not an adult, not even a kid. Nobody has asked to be born with an illness, nobody has asked to be sick or have a chronic condition.

As you see me you might think: "That girl looks pretty healthy and lives her life in a pretty good way," right? I can think; I can talk; I can eat; and I can walk. What else I can ask for? I am perfect!!

However, what about when I wake up in the middle of the night choking in my own blood because I had a nosebleed and my parents had to clean my bed, my sheets, my clothes, and my stuffed animals?

What about when I sit down during a school activity or PE class and am not able to play or exercise as a “normal” girl because it is too dangerous for me if I hit my head, my stomach, my inner arms, or my legs? My principal follows me around the school just to be sure I am ok and Patty, the secretary of my school, cleans my bleeding and calls my parents just to be sure that the hit I just had will not affect me or put me in a dangerous situation.

Or, what about when I lose a tooth? It is very exciting, right? What a special moment with the tooth fairy and the money under my pillow? Well, for me, my parents have to make a call with my specialist to ensure the treatment I have to follow so that I don't bleed a lot. If it is an extraction and if I have to travel 90 minutes round trip to get an infusion and come back to the dentist (because no single dentist will attend me without my special medication even if it is for a regular cleaning without a clearance letter from my hematology). Self infusion, liquid medication, nasal drops, pills or which medication I need to take 30 minutes before my dentist agree to see me? Yep, all of this just before the tooth fairy comes to my home at night.

What about when I reach puberty and I will bleed so much that I might need a blood transfusion like my mom because her monthly "lady days?" For me, I would have to self-infuse for several days every month with special medication that will stop my bleeding, take several doses

of medication at the same time and live with painful and heavy menstrual periods for the rest of my life? My parents have had the emergency plan for this moment since I was a baby.

I wear medical bracelet, silicone bands with the name of my condition, information inside my backpack with my emergency plan. I carry medication in my backpack. I have medication in my school, in my home, in my mom's purse, and in my dad's car just to be sure that I can be safe if I have sporadic bleeding or if I have an accident that will require and immediately care. When I travel in planes, a few times we lose flights. We have been placed aside waiting to be checked. My mom has been body-checked several times. My hands have been checked for chemical terrorist alert just because of my refrigerated medicine and a bag full of liquids, pills, syringes, and butterfly needles in a carry-on bag.

What about not the only one at home having these issues? Like mother like daughter, my mom's body and mine synchronize nose bleeds, gum bleeds. And daddy, he needs to take care both of us anytime of the day or night? Thanks, daddy for your support, your love and understanding about our condition.

We are spending so much time in emergency rooms because of our bleeding condition, so many nights with blood transfusions, with needles in our arms, running tests, losing a sibling because the bleeding condition. We are missing so many birthdays, so many Mother's Days, so many school days.... ahhh, I almost forgot.... We also canceled so many family reunions, family parties, trips, spring events, summer barbecues, beach days, Thanksgiving dinners, Christmas parties, New

Year's celebrations and more just because at any moment, anywhere at any time, we can have a sporadic, very long bleeding and a very messy dress. We, of course have to stay at home!!

I have a very rare disease called severe von Willebrand Type 1C, a genetic not contagious bleeding disorder that affects the possibility of my blood to clot properly. I do not have enough "glue" in my blood (the Von Willebrand protein) in order to stop my bleeding and I need special medication that helps with the process.

My severity consists of that I bleed externally and internally because is a combination of von Willebrand and hemophilia (they bleed internally). Von Willebrand is considered a "mild" disease. Can you imagine the people and the kids with hemophilia and other bleeding disorders?

Living in fear every day is not a game for me, neither for my mom or for my daddy. I have to accept my genetic condition for the rest of my life with patience. I am positive that someday scientists will find a cure. While that happens, I will be advocating for my disease, for my mom's disease, for my bleeding disorders community with our invisible illnesses.

While we wait for a cure, we have the best support for our bleeding disorders community. Not only are our specialists there for us, but also the National Hemophilia Foundation which helps us. We, as the bleeders, have the best care ever with full information about our disease, that provide educational programs to our parents and

caregivers, and we can learn more about our bleeding condition. We have events all year full of nice and cool activities for the whole family and a financial support when a family needs money for treatments, medication, travel expenses, paid hotels for seminars or meetings as National Hemophilia Foundation offers to all bleeding disorders families.

Thanks to the Connections for Learning grant and the National Hemophilia Foundation, my family and I will have the opportunity this year to travel to Chicago for their 69th Annual Meeting with a travel grant and we have the possibility to learn more about von Willebrand disease, about hemophilia, and about the new medications. We have the possibility to learn more about how special we are and meet people all around country like us. I am super happy because I know my parents are devoted to me, to understand the complexity of my rare bleeding disorder. They are thirsty for learn. They are devoted not only to me but also for our bleeding disorders community.

I can advocate more and help more people with this amazing opportunity thanks to the generosity of people like YOU that make this possible. Thanks to the generosity of hearts like yours, you are doing things for others because sometimes those things occupy the biggest part in others' lives, other human beings.

When you donate to a cause it is not only money you are supporting to an organization, it is the possibility to help others – to be in their hearts, save lives, and give hope.

Tonight, I am going to share the motto that inspires my life to do what I do, the reason of my life. John Wesley rules:

Do all the good you can,  
In all the ways you can,  
To all the people you can,  
In every place you can,  
At all the times you can,  
As long as ever you can

I am rare!! I am special!!! I love my life and I intent to live it in the best "normal" way possible. And most of all, I **challenge** YOU to give your support tonight. Don't just think about and listen to change, but be the change our community so desperately needs. You have that opportunity tonight to make an impact. Don't let it pass. Help us. Dig deep. Thank you for being here tonight.....

Thank you!