

Texas Bleeding Disorders Advocacy Coalition

The Lone Star Chapter is very excited to announce the formation of an advocacy coalition that will work for the

entire bleeding disorders community! Two of our young men, Robert DeForde and Christian Rodriguez

attended Hemophilia Federation of America's "Advocacy Intensive" training program in Washington, D.C.

Immediately upon returning from D.C., these two men called chapter President Brian Compton and proposed

the formation of this coalition. They presented at the November board meeting, and were met with great

enthusiasm. We all know that the bleeding disorders community must constantly stand up for what we want

and what we need. These two young men, and the entire advocacy committee will do just that!

Below, you can

read a little about their experience, and how you can get involved!

"We know what we want, we know why we need it, we know how we are going to get it, and together we are destined

for great things..."

It was too early in the morning and the night before we had not slept at all. We had been too excited to sleep because

we were headed to our nation's capitol, Washington, D.C.. We were looking forward to a weekend filled with excitement,

joy, and advocacy. We quickly got up, grabbed our bags, and headed off to the airport. As usual, Houston traffic was

bad, and like always there was an accident. It took forever to arrive, We finally boarded the plane with time to spare. It

was only then that we would realize that we were going to D.C. and that nothing was going to hold us back. Only then

too, we would meet each other and become good friends.

In early October we had the opportunity to travel to Washington, D.C. for HFA's Intensive program. Both of us have

agreed it is possibly the most amazing experience of our lives. We attended the intensive with 4 other active young men

from the bleeding disorders community, 3 from New York and 1 from Ohio. Each and every morning we awoke at 5:30

because our intensive meetings started at 7:00. We continued these meetings usually into the early evening, and over

the course of the week we caught ourselves becoming a type of brotherhood all focused on the same goal. By the end

of the week, we found ourselves staying up till 1:30 and 2:00 in the morning talking about different health care policies

and ways we could work to improve the current and proposed systems. We both agree that the brotherhood we formed

in D.C. is one that will not be stopped by the distance separating all of us. We hope to bring many more young men and

women into the program to find a way to be a voice in their community and an advocate for themselves. The

overarching theme from our time in D.C. was that we are all our own advocates and together we can make our voices

loud enough to reach inside the walls of our congressman's and senator's offices.

Now that we have arrived back home we have, with the guidance of several individuals and the support of our local

chapter - The Lone Star Chapter—organized a Texas Bleeding Disorders Advocacy Coalition. We hope that by

establishing this committee we can help members in our community and hopefully train many more people to become advocates. We have already formed an agenda for the next few months and for the following year. As of now, we are currently recruiting individuals from our community to attend Washington Days with us. However, not just any individuals, we want young, vibrant people between the ages of 18 and 25. More importantly, we are the future and the hope of tomorrow. Many of us have been in positions at times when we were down-and-out and absolutely everything hurts. We all know how that feels. So, now is your chance to chronicle all your feelings and all your ideas so that together we can make a difference. This community faces many issues such as access to health insurance, affordability issues, lifetime caps, pre-existing conditions, out-of-pocket costs (Tier IV), and a tainted blood-supply (many individuals in our community were infected with HIV and Hepatitis C in the early 1980's). We hope that anyone reading this that resides in Texas will contact us to join the advocacy group so that we may all make sure our priorities reach the desks of our elected officials. We must all remember we have and will continue to have a bleeding disorder for the rest of our lives. We will be walking the halls of Congress at NHF's Washington Days, February 24-25, 2010. We will keep you posted on our advocacy efforts. If you are interested in participating on the Advocacy Coalition, please contact us at TXAdvocacyCoalition@yahoo.com.

Christian Rodriguez is 23 years old and lives in Spring, Texas. He was diagnosed with hemophilia at the age of 3. He is studying both biochemistry and Psychology at the University of Houston, and is set to graduate in May of 2010. He hopes to one day attend medical school and become a doctor.

Robert DeForde is 20 years old, and lives in Friendswood, Texas. He and his mother both have von Willebrands Disease. He is currently a political science major and hopes to one day work in politics and run for elected office. Over time, Robert has realized that having a bleeding disorder is a gift he was given so that he might help the larger community of those with chronic disorders.