

“I’m able to do everything every other 22 year-old is doing and without it, I’d probably be stuck in a hospital. Infusions have

College Student **KARISSA YBARRA** Uses Her Experience with PIDD to Help Others

BY KYM H. KILBOURNE

IN FEBRUARY 2010, Karissa Ybarra, had the chance to visit a plasma collection center for the first time and meet the donors who contribute to the immune globulin therapy that makes it possible for her to live the typical life of a college student. It was an eye opening experience for her to share her story with donors, most of whom had never met someone who they have helped through their plasma donations, and to express her thanks.

The 22 year-old student at Houston Baptist University in Texas has been fighting a series of respiratory and other illnesses since being diagnosed with an IgA deficiency at 15 months only and, finally, with common variable immune deficiency disease (CVID) in her early teens.

Today, Ybarra, from Deerpark, Texas, not far outside of Houston, is an active member of the Immune Deficiency Foundation (IDF), helping young people cope with their disease through participation as a Teen Council mentor she travels to Washington, D.C. to meet lawmakers and to advocate on behalf of individuals with immune deficiencies as part of IDF’s annual legislative day.



At 18 months old, Karissa had been diagnosed with an IgA deficiency, which made it difficult for her to fight infections.

Early Diagnosis, Childhood Laced with Hospital Stays

When Ybarra was 15 months old, she was diagnosed with an IgA deficiency, one of the most common primary immune deficiency diseases (PIDD) that makes individuals susceptible to infection. Her mother describes her first year as one spent always sick and always in the hospital. When she was just over a year, Ybarra had become so ill with a respiratory infection that she was admitted to the

neonatal intensive care unit (NICU) on a ventilator at Texas Children’s Hospital in Houston. Finally, one of the doctors insisted that they would not leave until they knew what was the cause of the infection. Several different doctors were consulted including allergy and immunology specialists, who finally discovered the deficiency in her immune system.

Ybarra says that there was not much doctors could do for her IgA deficiency and she was constantly on antibiotics and suffering from skin and ear infections and respiratory illnesses. By the time she had reached her early teens, the illnesses became



Karissa and her younger sister Kaylie, who came to cheer her up at the hospital during Christmas time.

given me the opportunity to excel in all of the things I want to do and because of that I can live a very normal life.”

more frequent, causing her to miss school. Her illness eventually landed her in the hospital for a month when she was 15. Doctors eventually discovered that her IgA deficiency had progressed and diagnosed her with CVID. At that time, Ybarra began her first round of monthly intravenous immune globulin (IVIG) infusions at the hospital's allergy and immunology clinic that she continued until she was about 18. Now Ybarra takes weekly Ig injections that she has been taught to administer on her own at home.



Texas Children's Hospital

After a few weeks on the IVIG, Ybarra began to notice a positive change in her health and after two months, she stopped having reoccurring infections. A simple cold no longer turned into pneumonia, and her body could fight off illness.

Time as a Patient May Transform into Work as a Care Giver

Ybarra is now in her fourth year at Houston Baptist University, living off campus with the ability to administer her therapy at home. Luckily her roommates, whom she has known for years, takes everything in stride—spending time with her during her infusions, which can take several hours. She is majoring in psychology and child development and hopes to become a child life specialist at Texas Children's Hospital where she continues to be treated and where the staff knows her well. Ybarra describes the specialist she had as someone who, after her diagnosis, talked to her on her level and explained what was happening and how she would be treated. Child life specialists also work with the family, particularly other siblings, to answer questions and find out how

the family and young patient are coping, especially if the patient will need to undergo surgery and a sustained recovery. “Texas Children's saved my life a billion times and it is a special place for me,” Ybarra says. “I've gone through a lot there and I would love to be able to work there and give back.”

Mentoring Teens with PIDD

About two years ago, Ybarra got a call from Kathy Antilla with the IDF who had contacted Texas Children's Hospital to learn if it was treating any PIDD patients. Her doctor put the two in contact with one another, and Ybarra has been involved with the patient organization ever since, starting out as a member of the Teen Council and eventually becoming a mentor to the group, helping them plan events for young people with an immune deficiency and participating in a leadership conference earlier this year.

Ybarra says that her therapy has changed her life and the way she views things. “I'm able to do everything every other 22 year-old is doing and without it, I'd probably be stuck in a hospital. Infusions have given me the opportunity to excel in all of the things I want to do and because of that I can live a very normal life,” she says.



KYM H. KILBOURNE is PPTA's Assistant Director, North America Communications



Last year, Karissa traveled to Washington, D.C. as part of IDF's legislative day on Capitol Hill. She is pictured here with U.S. Rep. Kevin Brady (R-TX).