

To the CIRM Board of Governors, in support of Dr Bacchetta CLIN1 application 11591.

Intro: I want to thank Rosa Bacchetta, whom I met through my immunologist, for allowing me to come to the CIRM meeting on Oct 31st, and speak with all of you and provide a little background into my life for the past 28 years with IPEX.

- I was diagnosed with type 1 diabetes at 1.5 years old.
- Soon after being diagnosed with type 1 diabetes, I had to have a feeding tube inserted in my abdomen as I was restricted from eating almost all foods due to unknown food allergies. I was not allowed to ingest ANY food until the age of 6 years old. When I was finally introduced to food, any food ingested was tasteless and felt like sand paper on my tongue since I had to train myself to eat.
- Around age 10, I began a never-ending battle with dermatitis. I remember specific details of my first of many horrific battles with my skin. My mother had taken me to a dermatologist to try and figure out what was happening to my skin as it was red, blotchy, oozing and I remember shivering so badly that my mom had to ask the doctor's office to turn the air down. I sat in the doctor's office with a blanket, shivering, as my skin was not regulating temperature properly.
- I lost my hair at 18, and my skin started a battle that was more intense than any previous episode. I remember taking showers and clumps of my hair would fall out, and I would cry in the shower not knowing what was going on.
- Age 20, I would go through the most horrific episode with my skin to date. I was bed ridden, on pain meds and could not sleep. I had gone to all of my doctors trying to figure out what had triggered this event, and no doctor could figure out what was happening, leaving me extremely frustrated, depressed and drained of all energy. I went to the burn center as a last resort and was treated like a burn patient. To care for these wounds, I would bathe, take a sponge and physically scrape these open wounds to keep them infection free and as clean as possible. When I would exit the bath, I felt like a dried-up sponge and my skin was so tight that any movement would make my skin crack open and start bleeding.



- To regulate my IPEX symptoms, I took a series of medications. With medication, comes side effects. I have had at least 15 surgeries to remove squamous cells caused by one of the medications I had been taking. Then, I would endure one of the most difficult side

effects to date from one of my medications: In 2018, my colon perforated. As a result, I now have a colostomy bag.

- The IPEX symptoms have affected me not just physically, but mentally as well. I lost my hair around the age of 18, my growth has been permanently stunted, and I have not reached the point in puberty as my male counterparts. I would go day by day and see all my peers and be envious that they were tall, had beards and hair, had relationships, and the confidence that I was lacking and admittedly, still lack to this day at times. I've felt hopeless because there have been so few treatment options and with the treatment currently available, I only have horrific side effects to show for it. Not to mention, I have tried hundreds of medications and creams and have had my blood drawn countless times in hopes of finding a medication that works for me, or a cure for this insufferable disease. However, nothing. As a result, I have been battling depression since age 20. There were days that went by where I thought "I just don't want to be here if this is what life is going to be like." The funding needed for Dr. Rosa Bacchetta's research would be life changing in the way of new treatment options and potentially lead to a cure for this horrific disease. I am determined to see that there is so much more to life than what society is telling me. I've decided that I would not conform to societies rules, and instead, tell society how I am going to live my unique and authentic life with IPEX.

Taylor

Oct 22nd. 2019