That’s just the way I was made....
When I was 1 month old, my doctor told my parents that I have Severe Congenital Neutropenia.
I have to get a shot everyday. The medicine is called Neupogen.

My shots tell my body to make more white blood cells.

My shots help me to not get really sick.
I get my shots in my arms and legs. They don’t hurt too much.
One way that I know my shots are working to make more white blood cells is because I have to get my labs done at least every 4 months if I am healthy.
Another way that I know my shots are working is because every two years I have to get a bone marrow biopsy.

A bone marrow biopsy is when a doctor sticks a long needle in the back of my hip and takes some of my bone marrow.

The bone marrow tells my doctor how my white blood cells are working.
Some things that I do to keep germs from making me sick, almost everyone else does too.....
I wash my hands a lot.

I try not to eat too many foods that are bad for me.

I wash my scrapes and cuts really good.

I don’t drink out of the same bottle as someone else.
I am still aloud to do what normal kids do. I can...

Go to the beach, overnight camp, school, and play sports.

Really, the only things I can’t do are walking barefoot outside and swimming in lakes.
Every year I do a presentation for my class about Neutropenia. They think it is really cool.

I also like to do fundraisers to help support Neutropenia research and raise awareness for Neutropenia.
I am hopeful about the work that some researchers are doing for Neutropenia.

I have heard that the researchers are currently working on a few things that I am excited about. The first is a pill that I might be able to take instead of a shot.

I also heard that they are working on a kit that might let me check my white blood cell counts at home.

How cool would that be if I could take a pill instead of getting a shot and no more going to the lab to get my blood drawn!!

I know these are still being researched, but I am going to keep my fingers crossed!!
Even though I have Neutropenia, I really am just a normal kid. If you have any questions, just ask!

Now my brother, Evan, is going to tell you about his experience having a brother with Neutropenia.
So, you may ask,

“What is it like to have a sibling with Neutropenia?”
Although I was 2 when Liam was born, I was probably 3 when I kind of understood what Neutropenia is, and I thought, “Well it can’t be that bad, right?”

But over the years I have learned the exact opposite.
Having a brother with Neutropenia is tough. I have to help out all the time when he is sick and help keep our younger brother brave when Liam is in the hospital so he doesn’t get scared.

Neutropenia can be hard for kids, but if they know what it is and stay brave, they might find that it doesn’t have to effect what they can do.

It seems like Liam is not greatly effected by Neutropenia because I play with him like he is a totally normal kid. It also seems like this because when he is in the hospital, he always has a positive attitude and can find a silver lining in everything.

Liam is just as goofy and funny as everybody else in the world!
But how I know it effects him are by these things:

* Labs at least 6 times a year
* Hospital visits at least 1 to 2 times a year
* Caution for infections
* Shots every day
* Bone marrow biopsies
* Always has to wear his shoes outside (except at the beach)

But during these times, he is **always** brave!
Despite all of these things, Liam’s attitude about his Neutropenia helps to keep things in perspective.

Check out this cool thing he recently said to my mom....

“ If I didn’t know what Neutropenia was, I wouldn’t like it. But since I know what it is, I actually kind of like it. I don’t like what it does to my body, but it is who I am. It is what makes me, me.”
If I were to say anything to kids with Neutropenia, you know, from a sibling perspective, I would say....

”Be brave! Be as goofy and as funny as everybody else in the world!”
Thank you for letting us share our experience with you today.

We hope that you enjoy the rest of the conference.