



## *"Kallan-isms"*

**Kallan-isms are little stories about Kallan in her journey to be cured from Pediatric Cancer.**

**They are meant to show us and teach us how to live our life. If you are having a bad day, read a few Kallan-isms, and you will realize that what you are experiencing and feeling is silly.**

**Kallan-ism #1: The history behind "What are we Doing tomorrow" July 2005. Kallan was in Hershey Medical Center for her stem cell transplant. This was her second bout with a Medulloblastoma, and the previous high-dose Chemo's shrunk the spot on her spine down to a dot. The stem cell transplant was supposed to kill the spot and all the microscopic cancer floating around in her Central Nervous System.**

**When Kallan would go into the hospital, she hated staying in her room. She would either make dad push her down to the play room in her stroller and drag**

the iv pool too, or they would be in the cafeteria eating and just sitting there, or they would be in the family room at the other end of the hospital. Anywhere but her room. But during transplant, Kallan was not allowed to leave her room - for 50 + days.

After about a week, Kallan did not want to do anything, she looked depressed and dad had to think quickly. So, he took out a piece of paper and a pencil and started to try to entertain Kallan. He said, "Let's make a list of what we can do today.", trying to give her something to look forward to.

This perked Kallan up, and she made a list of all the activities they could do, everything from coloring, to making a tent in the room and "camping" out.

After that, Kallan did this every night during transplant, and when she went home, and every day after that until her death. She never wanted to let a day go past that wasn't planned out, or miss an opportunity to do something that she enjoyed. Every day was planned out to the hour. It was one thing that Kallan will always be remembered for.

Sometimes, it seemed like Kallan knew she only had so long on earth, just like all of us. The difference is that Kallan did not waste even a minute of her life, she lived it to the fullest.

**Kallan-ism #2 - Kallan loved her friends very much, but she especially loved her little sister, Krystian. When Kallan had to be away from them when she went to the hospital or to clinic, it would really bother her.**

**So, while at the hospital or clinic, Kallan would want to know what her sissy or friends would be doing - every 5 minutes !!**

**If it was 10 am, and we would be sitting in the infusion room in clinic, she would ask, "What is sissy doing ?" So, we would go thru sissy's day care schedule.**

Kallan was always more concerned about how sissy and her friends were doing and if they were ok, than what kind of poison they were pumping thru her veins that day. She always wanted to be assured that they were ok.

**Kallan-ism #3** - During Kallan's last relapse, we spent a lot of time in New York City at Memorial Sloan-Kettering participating in a Phase II Clinical Trial. Prior to being able to undergo the trial, Kallan needed surgery on her spine to remove one of the cancerous lesions that was too big for the medicine to kill.

Prior to surgery, we told Kallan that the Neuro-Surgeon said that she could go home in 3 days after surgery. Kallan used that as her motivation.

After surgery, Kallan was both angry and in pain from the spinal surgery, and we worried because the Neuro-Surgeon had told us that there was a slight risk if he nicked the spine, she may not ever be able to walk again.

The first two days after surgery, the Neuro-Surgical residents would come in, and Kallan would refuse to move her legs so they could see if she had any feeling in her legs. She did not like them, because she did not know them, and she did not want to be their "friend".

On day #3, Kallan woke up and said to her dad that she was ready to go home. Her dad explained to her that she was not even out of bed, so "don't get your hopes up honey, because they will want to see you walk before they let you go." Kallan was pissed and said "I want you to tell him we are going home today."

When the Neuro-Surgical residents came to do their rounds, Dad explained to them what the Neuro-Surgeon had told her, and they laughed and said, "Not until she gets out of bed and walks."

Now, Kallan had not moved her legs since her surgery, but she was in a foul mood when she heard this. Kallan looked at the Neuro-Surgeon resident, and in her most serious voice said, "Fine !!" She threw back her covers, put her

legs over the bed, and slowly stood up !! She then took a few steps, looked up at the Neuro-Surgeon and said, "You said I could go home when I walked, well, I walked, now let me go home !!"

Both Dad and the Neuro-Surgeons were so shocked, they just looked at each other. Finally, the Neuro-Surgeon said, "Ok, but you need to stay at least one more day, if that's ok." Kallan agreed, but said, "that was it !!"

Kallan had more determination to get better, be home, and be normal than anyone I had ever met. She taught me what real strength is all about. Pound for pound, she was stronger and tougher than anyone I have ever met or ever will meet.

Kallan-ism #4 - During transplant, Kallan would refuse to lie in her bed during the day. She would wake up at her normal time, make dad give her a bath, get dressed in normal clothes, and then sit in her chair with her Barney to do an activity, or to watch tv.

Her Oncologist would come in and say, "Kallan, you need to lie down and rest so you get better." Kallan would just shake her head no.

Day after day, this would be Kallan's practice, and day after day, her Oncologist would come in and tell her the same thing.

Finally, her Oncologist came in and said that in 20 years, she had never seen anything like this. She said usually, she can't get the kids out of bed. So, she asked Kallan, "Why don't you lie down in bed so you get your rest ??"

Kallan looked at her and with the most serious voice, "Bed is for night when you sleep, not for day. When it is day, I will sit up in my chair. I am FINE !!"

This determination sustained Kallan during her journey. She was stubborn and determined to be just like everyone else.

Kallan-ism #5 - Kallan and her sissy were very close. They took baths together, were put to bed together, and did everything else together too. They were more than sisters, they were best friends, and Krystian worshipped Kallan.

About a month before Kallan died, Kallan lost her ability to walk and was in a wheel chair. About this time, Kallan started to become very mean and angry towards Krystian. She wouldn't play with her, she wouldn't sit with her, and every time Krystian tried to talk to Kallan, Kallan would just snap at her.

Finally, dad had a talk with Kallan because he could see how much this was hurting Krystian, and this was just not Kallan. Dad told Kallan that Krystian just loved her, and wanted to show her that.

Kallan said to her dad, "Krystian is always saying that she wants to be just like me, and I don't want her to be daddy. If she is just like me, than she will get sick too, and I don't want her to be sick. I don't want her to be like me."

Kallan's dad was stunned by this. Here was a 7  $\frac{1}{2}$  year old girl who was very ill, couldn't walk anymore and was very upset she couldn't be like the other boys and girls, and the only thing she could think of was her sissy being ok.

Her daddy explained to her that by sissy wanting to be like her, didn't mean she wanted or would be sick. Her daddy told her that she wanted be brave and strong, like her big sissy, and that it was ok to show her how much you love her.

Kallan thought about that for awhile, and after that was a little nicer to Krystian. It wasn't until the night of Kallan's death, that she took Krystian's hand, looked her in the eyes, and said, "I love you too sissy." These were the last words Kallan spoke to anyone, and Krystian speaks of this every single day. It was a blessed gift from Kallan to Krystian that will never be forgotten.

Kallan-ism #6 - During Kallan's 4 years of therapy in her fight to beat her cancer, Kallan not once complained of any pain. No matter what the problem was, she refused to admit that she was hurting. There were two reasons for this, 1, she was always afraid that if she admitted she was hurting, Dad would take her to the hospital, and 2, she did NOT like Pain Medication. This was never more evident than during her Stem Cell Transplant. Her Oncologist told us that after the high dose Chemo, that Kallan would get Mucositis, which is a condition that Kallan would get sores in her mouth, down her throat, in her stomach and all the way thru her digestive tract. They would be so painful that Kallan would not be able to drink or eat, would need morphine and a morphine clicker and would be fed IV. Everyday, Kallan's Oncologist would come in and ask Kallan if she was in pain, and everyday Kallan would shake her head no. Finally, her Dr said, "She must be in pain. She has sores in her mouth and refuses to eat or drink." Since Kallan would not admit to it, her Dr decided to start monitoring her blood pressure. As the pain got worse, her blood pressure would start to go up. Sure enough, her blood pressure starting to spike up and down, all due to the pain that Kallan refused to admit. Her Dr finally decided enough was enough, and she put her on Morphine. Kallan finally was able to rest once her pain was under control.

Sitting there watching her fighting that pain off and not letting it overtake her was an amazing thing to see, especially when it is your child. It made me realize that if anyone could beat this disease, against all the odds, Kallan would, or she would fight to the bitter end. She did not win her fight, but she did fight to the very last breath.

Kallan-ism #7 - Over the years that Kallan was sick, she would constantly teach me lessons of strength. One such lesson happened during the final relapse she had. Kallan loved school, and missing so much school due to appointments made her very upset, so when she could go to school, nothing would stand in her way.

One day Kallan got up on a school day, and just did not feel well. She had just started a new cycle of oral chemo, and her stomach was upset and just did not look good. I told Kallan she would need to stay home from school that day. This upset Kallan a great deal and was not very happy with me. She pouted and refused to talk to me. Finally, Dad said that I would let her go to school, but I was taking her in so that I could alert her teacher that she was not feeling very well.

Kallan did not look good getting ready for school and on the ride to school, so Dad was second guessing his decision. We walked into school and into her class room where all her friends were already sitting at their tables, and what I saw next absolutely amazed me. Kallan marched into that classroom, took off her coat, unloaded her backpack and marched right over to her table with a big smile on her face like nothing was wrong. It was a complete 180 degree turnaround. I leaned over to kiss her good-bye, and Kallan said, "See Daddy, I'm fine. I am always fine here at school. Have a great day !!"

Her desire to be like the other boys and girls helped her overcome a lot that us adults never could. Examples of her strength and courage helps me go from day to day without her.

Kallan-ism #8 - During the 4 years and 11 days that Kallan was sick with her cancer, I can count on three fingers the number of times that Kallan was scared about anything. One such time was shortly after Kallan lost the ability to walk and was in a wheel chair. She so desperately wanted to go back to school to see her friends and to catch up on her school work.

Dad went in and convinced the school that she would be ok and that I would be Kallan's aid until they were able to find a medically trained aid for her. I was very excited after talking to the school, so I rushed home to tell Kallan, and all of a sudden, Kallan was not so excited.

The next day we got ready for school, put her wheel chair, her backpack and all her goodies in the car and went to school. When we got there, dad got

her wheelchair out and was ready to lift Kallan out and take her into class. All of a sudden, Kallan put her hand on my hand and said, "Daddy, I'm scared." as she had tears in her eyes. I said, "What's wrong honey ? Why are you scared ? " Kallan went on to tell me that she didn't think her friends would like her anymore since she couldn't walk, and she was scared about her friends not loving her as much as she loved them. I explained to Kallan that it wasn't her walking that her friends loved, it was in her heart and the way she treated them. Kallan seemed to understand that, but still, she was scared.

We proceeded to go into school, down the hall, and into her classroom. What I saw next, will be a memory I will always take with me. All the kids in her class stopped what they were doing, ran over to Kallan and wanted to know how she was doing, how they could help, told her how much they missed her and loved her, and one little girl even took Kallan's hand and told her that she "could not sleep the previous night because she was so excited to see her."

I often wondered, why all the medicine that Kallan took in the 4 years and 11 days she was sick, could not be as effective as the love of those children that day and all the days Kallan was sick and in school. If it could have been as powerful, than my little angel would be cured and be here this day. The love of her friends and family could not cure Kallan, but it made her so very, very happy, and I could not have asked for a better day.