

Island of Hope's 25th anniversary: Honorary survivor Joe Slachciak's story

**STORY AND PHOTOS
BY SENIOR CONTRIBUTING
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Relay For Life's honorary survivor, Joe Slachciak, loves superheroes, cooking and YouTube. He said that he admires all superheroes but that his favorite one is Spider-Man.

"He's cool and he's strong," Joe said. "He solves crimes. Saves people."

Not only is Joe a fan of Spider-Man, he is also a fan of the actors who have portrayed Spider-Man.

"I like Tom Holland, Andrew Garfield and Tobey Maguire," he said.

Joe, who is the fourth of seven children, is a true middle child, said his mother, Sara Slachciak. Another thing that makes him unique is that he is her only child to have Down syndrome.

Sara said it was her son's interest in superheroes that resulted in his being chosen to be honorary survivor for the June 6 event.

"We are definitely a superhero kind of family," she said.

Joe's father, Kevin Slachciak, is the owner of Say Cheese Pizza Company & Comic Book Café on Love Road.

"(Relay For Life Co-Chair) Lynn (Dingey) reached out and asked, especially because it's a superhero-themed year," Sara said. "Joe was telling me that he'd like to be Spider-Man."

Joe, now 18, was diagnosed with leukemia shortly before he turned 17. He spent a month in Golisano Children's Hospital of Buffalo before he went home to continue treatment on an outpatient basis. Because he has been undergoing treatment, Joe, who is being homeschooled, has not been able to attend the School of Two Hearts, a cooperative for homeschooled children, located in Cheektowaga.

"Joe gets opportunities to do all sorts of different things, like culinary. He likes history there," Sara said.

Joe added that he also likes math, gym, soccer and football.

"In the fall, he will go back," Sara said. "He will be able to pick which classes he wants to take there, stay after for gameday on certain days when he can stay after and play board games."

He also enjoys YouTube. Joe has his own YouTube channel called "Joe's Corner." He and Kevin make videos together about his treatments, Joe's experiences in the hospital, cooking demonstrations or anything else Joe enjoys sharing. Foods that Joe enjoys talking about and preparing include pizza, and chicken salad with mayonnaise and pickles. Sara said his favorite food is a tomahawk steak.

"Joe is in the final phase of his treatment for leukemia," she said. "Pump maintenance. It will be just under a year for this stage. Joe is doing really well. He's back to going to the gym."

"I like pushups," Joe said.

Joe first began going to the Medically Oriented Gym (MOG), at 1801 Grand Island Blvd., for physical therapy.

"But now, he's graduated from physical therapy and he's able to go to the gym with guidance, and he's enjoyed that very much," Sara said.



Joe Slachciak, right, and his father, Kevin Slachciak, at Relay For Life. • Above, Joe Slachciak.

Sara explained how it was discovered that Joe had cancer.

"We saw some signs we didn't realize were signs. He was sleeping a lot. Overall, he was just kind of blah. He was complaining about some leg pain. But none of these was anything that would be concerning in themselves. But (they were) as a whole picture, in hindsight. ...

"The (symptoms) can all be chalked up to being 16. Sixteen-year-olds like to sleep a lot. Sixteen-year-olds don't really want to do what their parents want them to do. Sixteen-year-olds can have growing pains. These are all things that are not alarming in themselves.

"People with Down syndrome are prone to having thyroid issues. Joe has been tested in the past. He really didn't have an issue, but I thought maybe this is a thyroid issue. We took him to a pediatrician. They ran some basic blood work. That was, I believe, on a Thursday. The pediatrician called on Monday, and the pediatrician said, 'You need to take Joe to the ER right now. Do not pass go, do not collect \$200. Go to Children's right now.' His platelets were super low. His white blood cell count was super low. It was very, very concerning. So, that's what we did. We grabbed a coat and went. It was maybe 8 o'clock at night. Joe spent about a month.

"Joe got to spend his 17th birthday in the hospital. They got him his favorite doughnuts. They decorated our door. They got some special toys."

"I got a Baby Yoda," Joe said.

"From 'The Mandalorian' show," Sara noted. "Even though he had to be in the hospital for his birthday, I would say the day it started being a little less scary was when we had a diagnosis. At least we knew what we were dealing with. We know that, 'OK, we can deal with this.' The unknown is sometimes scarier.

"We were at least given the information that we needed to say, 'OK, this is what we're going to do.' Children with Down syndrome tend to respond better is what I feel I was told. That was a positive thing. And then, Joe just being so easy going and laid back about the whole thing. He never

complained once."

When asked how he felt about being in the hospital, Joe said, "I liked it."

"Joe loves the hospital," Sara said, "The nurses were all so wonderful.

"Joe is the best patient ever. He is so cooperative. It doesn't hurt that we have wonderful care here in Western New York at both Roswell and at Children's. We have the best home nurse ever. Joe is just a trooper. He never complains. He takes it all in stride. It has been tough, but he's done a great job.

"Joe has such an exceptionally good attitude all the time anyway that it's really been the best possible experience, if that's even a thing during cancer treatment. He's so easy-going and he's so willing. Your typical teenager would be losing their mind if they had to spend a month in the hospital without their friends and their Snapchat and all their favorite sports. Joe has always been such a happy-go-lucky kid. He can be mischievous.

"The type of cancer Joe has is very common amongst children with Down syndrome. They typically get it much younger. We thought we were kind of out of the woods with this. Usually, they get it between the ages of 1 and 10.

"(The doctors) are learning new things all the time. What works, what doesn't work. Joe happens to have this kind of leukemia at a great time because the immunotherapies are finally being approved for children. They've had great success with adults. But it takes forever for it to get approved for children. Joe was able to benefit from all those years of other children maybe not having such great experiences. They didn't have the opportunity to get those drugs. Timing is a thing as well with this. Had he had this when he was younger, he would have never been able to have those treatments.

"He's doing great. The immunotherapy that Joe has gotten has just been approved for children within the last year. That's amazing."

Joe has also had the opportunity to take a break from treatment. Recently, he and his family took a trip to Las Vegas.

"We went to the Spy Ninja headquarters," Sara said. "The Spy Ninjas are YouTubers that Joe is really fond of. So, they have their headquarters in Las Vegas. We got to go there. It's been Joe's dream ever since they announced that they were building it. It was really amazing."

"We got to go to Hell's Kitchen," Joe said.

"That's Joe's other dream of going to Gordon Ramsay's restaurant out there," Sara said.

"I ate the beef wellington," Joe said.

"That's what they're famous for," Sara said.

Another one of Joe's dreams is to be a famous YouTuber.

"There are some videos on there from Joe's trip to Vegas," Sara said. "You can see what he got to do there. He started this channel pre-cancer diagnosis, and it's always been Joe's dream to be a famous YouTuber. He's quite interested in other YouTubers and their content. There are

a few videos on there precancer. It was super helpful to be able to get information out to people. People know that something's wrong. You have time to respond to all your family and friends, who have lots of questions and are very concerned. It's been a blessing to be able to get that information out to people in a timely fashion. Joe has enjoyed getting to update people."

Sara also is a cancer survivor. She had breast cancer, which was treated with surgery, and she is now in remission.

"One of the things that I've noticed about having cancer is the survivor guilt," Sara said. "It's a real thing. Even when it's your child who has cancer. You see these children on the same floor as you. You're so grateful that your child is doing so well, but then you meet families, and you see these other children. They all have different types of cancer, and it's not ... we don't always know what's going on. Then you see that they aren't doing well, and they won't get better. Some of them. It's heartbreaking and terrifying and that part is the most scary. You don't want it to enter your thoughts as a possibility.

"We keep going forward. We follow the calendar. We're trusting all these people who are our caregivers, our team. You have to trust that they know what they're doing and keep you on track and it's all going to be OK, even if it takes a few years. You're going to be OK.

"We can't know what we don't know. We just make the best decisions we can with the information we have. We have to just do our best. That is one of the hard part of things. Children who don't make it. It's so awful. Nobody wants to talk about it, I don't think."

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