

Sevanah's Journey

Wendy Marecle (Kiwanis Club of Belleville)

What is a Child Life Specialist? I call them the lifesavers of sanity when your child is sick. My daughter, Sevanah, was diagnosed with stage IV cancer at the age of 5. The medical team at Mott is fantastic. Child Life Specialists at Mott, they take care of fun and help your child learn about the procedures and their disease through play. They provide fun projects to distract a child's mind from all the things that they can't control that are going on in their body.

That first day we entered the hospital in a fog. We had no idea what just hit us. Coming in to the Emergency Room for fever and severe pain that night to being told that Friday morning that our daughter had an abdomen full of tumor. Our heads were spinning. We were admitted and immediately the testing started. We left the room that morning and we were gone for 6 hours before we finally returned. Xrays, bone scans, heart echo, ct scans, it was a blur. Her meds had worn off by the time we returned and she was really in a lot of pain again. We met so many people that day including the Child Life staff that was there trying to see what they could do for us. We would continue to have them pop in the room everyday. As it turned out from the testing they knew that Sevanah's cancer had spread from her kidney to her lungs and liver, as well as in the abdominal cavity too. We were told they would need to do surgery to remove the mass and make a full evaluation of what we were dealing with. They had pretty much narrowed it down to being one of two different cancers based on the testing but needed to have the pathology report after surgery to confirm a definitive diagnosis.

Surgery was planned for Monday morning. Jenny, one of the Child Life Specialists on the 7th Floor, sat with us and both of our little girls on Sunday and used dolls that the girls were able to help design to help explain the surgery and the port placement that would happen very soon. She explained how the port would help get the medicine in that she would need to help her get better and it would save her from being poked so many times a day.



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Sevanah had months of chemotherapy and radiation treatments as well as many trips to the operating room over the course of that year. Child Life was there for everything. Port access was the one thing that Sevanah fought horribly. She never got comfortable with the idea of that big needle being poked into her chest. They tried distractions, numbing cream, everything. It was a traumatic experience every time having to be held down so they could access the port to save all of the extra pokes and be able to easily administer the meds without an IV every time. The Child Life Specialist would be right there trying to calm her, offering her toys and crafts to help calm her after the access was complete.

Many of our extended hospitalizations included being in isolation. They would bring video games, movies, and crafts to her room. Sevanah truly developed a love for arts and crafts during this time. She is still inspired to be artistic and creative today. She has even said she would like to be an artist one day. On the days she was being isolated due to complications she would be able to play in the Child Life Play Room. That was especially nice when her sister, cousins, or friends came to visit. It gave them a creative place to play safely and not be in the patient room with little to do. Someone donates wooden shapes to the hospital on a

continuous basis for the kids to paint. All of the kids love to paint these shapes. Honestly, we still have many special wooden animals that were painted by my kids all those years ago.



I remember the project that the kids were painting tiles that would be placed in the new hospital when finished. They are so interesting to see them all on every floor of the hospital. Sevanah never did get the chance to do one because she was too sick at the time. However, after the tile project was complete and they moved to the new hospital they did ask her to design a picture that could be framed for the hallway. She made a picture with gold ribbon that says HOPE. If you are ever on the 7th Floor in the clinic area you will see her picture still hangs there today.

There are so many memories and new ones created each time we go to clinic or the emergency room. Sevanah is a two time cancer survivor that has experienced many complications and secondary issues along her journey. With 16 different specialists at Mott that oversee her care, we also see our friends in Child Life frequently. There have been visits and gifts from Santa during clinic, Buzzy the little device that helps with pain reduction, movie goggles with headphones to help with anxiety during an MRI, hope beads that helped Sevanah document part of her journey in a really long bead necklace with a bead for each procedure, iPads to play games to distract during procedures, the family center to visit as a family or part of the family during sibling visits, and so many more things to help the entire family cope with the hospitalization of their sick child.

I didn't really know who provided the financial support for these type of programs. I knew the hospital had donors but specifically what Foundations or individuals supported this were really not on my mind. I joined Kiwanis when a new club started in our town less than two years ago. What I found in the Kiwanis organization is a ton of people that love to help kids in their communities and around the world. I also found a couple of books recently that we received when in the hospital that had the Kiwanis logos inside. Within the Michigan District, I then discovered the Kiwanis of Michigan Foundation. This Foundation supports the Child Life Department in four hospitals in Michigan including Mott Children's Hospital. I am so honored to be a part of an organization that supports these programs so generously. I know personally what a difference this makes to a family with a sick child and I know all too well that there are hospitals full of sick children unfortunately. Even though I didn't know about Kiwanis in the beginning of our journey, Kiwanis was there helping all along.