

HEALTH

# Trend

SACRED HEART HOSPITAL

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*J.P. Suchcicki*

A STORY OF SURVIVAL:  
**Through the Eyes  
 of a Parent**

*By Mike Suchcicki*

**S**ometimes it seems like it was all just an episode in our lives, a chapter that came, had its impact and then left to make way for other, happier, chapters.

Sometimes, when we're packing our sleepy, reluctant 9-year-old and his 7-year-old sister off to school, or when we watch him trade superhero cards with his friends or listen to him tell a silly joke that turns him red with laughter, that year and a half of hospitals and magnetic resonance imagers seems like just a dark blur.

Just an episode.

After all, J.P.'s hair has grown back, perhaps not as red as it used to be, but long enough, at least to cover the radiation-burned patch in back that will never produce hair again, and hide the surgery scar that runs down his neck parallel to his brain stem. He's gained weight and regained the color in his skin. He's taller and older and has outgrown the Ninja Turtle and G.I. Joe pajamas he used to wear in the hospital. He no longer carries the mediport under his skin on his right shoulder, once the connection point for the chemotherapy tubes he endured each month. He no longer stares off into space with a blank expression—unless we're talking to him about homework. He smiles now.

My wife Lani and I have to use other ways to remind ourselves that our son J.P. is a survivor of a most dangerous type of brain cancer.

We have to remind ourselves that J.P. is, to use the expression,

not out of the woods yet. More and more, however, we allow ourselves the privilege of forgetting. He's a crazy, happy kid and if sometimes we forget to remind ourselves of how serious it was and how serious it could be, well, we don't punish ourselves. We play with our son.

It was Thursday, Aug. 15, 1991, at about 10:30 in the morning, when we first knew J.P. was ill.

There had been signs before, though we didn't know it. He was often moody, sometimes downright cranky; he bumped into things. Trips to the doctor had revealed ear and sinus infections and we thought that was that. He never complained of headaches, had no fevers.

On that Thursday morning we had just taken J.P.—Joseph Paul—to his second-grade orientation. He had been even more moody and disoriented than usual, to the point of crying when the teacher asked him to do a small craft project for the bulletin board. We suspected another ear infection and had planned to call the doctor later that day.

But as we left orientation, J.P. suddenly stumbled and fell. What happened, we asked?

"I didn't know which sidewalk to walk on," he said. He had been seeing two sidewalks. In fact he had been seeing two of just about everything and hadn't told us.

We made an appointment with his doctor immediately. She also suspected an inner-ear disorder, but ordered a CT scan "just in case"

"In case" happened. A golf ball-sized tumor was found on J.P.'s brain stem and he was admitted immediately to Children's Hospital at Sacred Heart. This was Thursday; he was scheduled for surgery the following Tuesday.

Some friends and family members had suggested we not tell J.P. that he had cancer; after all, he had suffered with us through the death of his grandmother—my mom—of stomach cancer just the month before. Lani and I made the decision to tell J.P. exactly what was happening. True, we tried to use the C-word sparingly, but we were determined to be honest with him.

He took the tour of Children's Hospital and learned more than he ever wanted to about anesthesia and IVs and intensive care wards. Needless to say, he discovered the first-floor playroom and spent many hours there over that long weekend.

Tuesday finally came. Perhaps my most vivid memory of that entire time was seeing my seemingly healthy son lying on a gurney, covered with a silver blanket, nervous but otherwise quiet. Inside I was screaming, because I knew that even after all the explanations and tours and discussions with doctors, he had no idea what was about to happen.

Waiting for an operation to end is a long, hollow time. Nothing registers and nothing else matters. When the surgeon came to the waiting area, we realized it was not the end of an ordeal but the beginning.

J.P.'s tumor was a serious malignancy known as medulloblastoma—a word we had never before heard but will always remember. More than 90 percent was removed, but a tiny sliver remained imbedded in the brain stem; it was too dangerous to remove.

The J.P. we met in the intensive care ward was no longer the boy we had raised for seven years. He was shaved bald and bandaged, pale and taped to an IV. He didn't cry; he wailed. He was in pain and disoriented by the surgery and the medication. Throughout the next five weeks we spent with him in the hospital, we despaired of ever getting back the son we knew.

I still remember the night of September 3. It was my turn to spend the night in his room at Children's Hospital. He had been released from the ICU and was on the third floor, the floor that would be our second home for the next year. It was my birthday.

It was two weeks after the operation and J.P. still was not talking. He pointed and grunted. None of his doctors could tell us if this was a temporary effect of the medication or a permanent effect of the operation. He liked to ride in the wheelchair, so we took him around the grounds as much as possible. Late that night he pointed to the wheelchair and grunted that he wanted another ride. As I took him through the hospital he sat huddled in the chair, wrapped in a blanket, his head bowed, silent.

Frequent visitors know of the tunnel that connects Children's Hospital with the main hospital, the

one lined with large, colorful letters of the alphabet. Whenever J.P.'s mom would roll him through the tunnel, she would read the letters aloud. On the way back, she would read the alphabet in reverse.

That night, rolling him through the tunnel, I heard strange grunts. It was J.P. "What?" I asked, and leaned down to hear better.

He was saying the alphabet in reverse, one by one as we passed each letter.

Whether he was reading it or reciting it from memory, it only meant one thing: he was in there somewhere, fighting to get out through the shroud of medication and scar tissue. We hadn't lost him.

My scream of joy echoed through the tunnel. I hugged J.P. and even got him to crack a little smile. I took him back through the tunnel and he read or recited each letter, back through once more and he recited it again in reverse.

I called Lani with the joyous news: J.P. was coming back, slowly but surely.

He is back, after six weeks of radiation and 10 months of return visits to Children's Hospital for chemotherapy and more wheelchair rides through the tunnel. The tiny sliver of tumor imbedded in his brain stem seems to have disappeared. MRI scans are negative. The treatment worked.

He smiles a lot now and tells jokes and picks on his sister. He just started the fourth grade.

He's the J.P. we knew before this whole terrible thing happened.

Yes, sometimes Lani and I have to remind ourselves that he is a survivor of cancer and we have to remind ourselves of the dark clouds we all once lived under, dark clouds that may someday return.

But then we watch him double over with laughter at one of his own silly jokes, and we make a mental note to remind ourselves some other time.

