



American Childhood Cancer Organization Inland Northwest Helped My Family

by: Jamie Hansen

The first time I heard of American Childhood Cancer Organization Inland Northwest (ACCOIN) {formerly Candlelighters of the Inland Northwest}, we were in the hospital with our 8 yr old daughter, Thalon, and living the worst year ever. The first half of the year, my husband was sick and unable to work. A surgery in July took care of most of his symptoms, but the day he returned to work, I fell and broke my ankle. Because I have Friedreich's Ataxia, a hereditary, progressive neurological disease, this normally minor accident took me from walker to wheelchair instantly.

That September, Thalon was 8 years old and had just begun 3rd grade. She was at that beautiful stage where she still looked baby-cute but had moments of looking so much older. My best memory of that year was her walking along the sidewalk, dragging her backpack-on-wheels, in a black dress and inch-high heels, her blonde hair twisted up in a clip and her arms thrown wide as she sang to the sky.

While teaching her to crochet, I noticed her arm shook and her fingers weren't grasping the yarn well. Added to her black eyes from walking into doorframes (and any clumsiness that labeled her "clearly" my daughter) and headaches whenever she had to exert herself (read: clean her room), we knew this was more than just a phase.

For three months, we fought the battles of doctor's appointments and insurance, anxiously watching Thalon's arm shake more and her left leg begin to drag. By this time, we were getting phone calls from her teacher and the school nurse. The day after Thanksgiving 2003, she finally had her appointment. We were told it was only the first of many tests and were trying to be patient.

But, they found something. An egg-sized tumor in Thalon's brain. We were immediately admitted into the Sacred Heart's Children's hospital. Thalon was one of the first few patients in the new Pediatric Oncology ward and she was scheduled for surgery the following Monday, December 1st. Two weeks after that, she was transferred to St. Luke's Rehab until her birthday, December 24th.

Thalon had cancer, a Thalamic Ganglioglioma. She was home for one week after Christmas, then admitted on December 31st to have a port put in. She had her first chemo treatment while watching the downtown fireworks from her hospital room.

Everything happened so fast, in such a whirlwind we were dazed and confused. We had family and friends, people who'd stood by us all year, but there's only so much they can do. At the end of the urgency, they needed to return to their lives. And there were new friends at the hospital who didn't have a family to fall back on at all, so we were very thankful for all the help we did have. But there comes a point where you are in it alone, just your household.

Except ACCOIN, an organization of parents and patients who have all been there and who understood exactly. They gave us a welcome bag with necessary information about cancer and different resources to help. They helped with practical gifts, like grocery & gas gift cards when, as the only able bodied driver, Craig had to quit his job and take Thalon to appointments five days a week.

Her treatment began as a 12 month plan, but turned into 16 months with six surgeries. She was stuck with so many needles, sometimes only the thought of her “poke” prize helped her through it. And when her appetite declined, the snack basket at the hospital was sometimes all she could manage. ACCOIN provided those, as well as fun activities: picnics, river rafting, Wild Waters, the annual Christmas party. There were affordable, safe places for Thalon to have fun while in treatment, where everyone else was as conscientious about sniffles and coughs as we were.

Thalon is now 14 and finally able to join the teen group. Just a week ago, they attended the teen Christmas dinner with siblings and friends. As the effects of childhood cancer never quite end, it is wonderful for her to have such a supportive net around her. ACCOIN pulls us together so none of us are completely alone when devastation overwhelms us.