

**UVic Diversity Writing Contest 2011,
Personal Narrative First-Place Winner**

By Jerold Flexer

Victory, My Son

Vancouver General Hospital. 4:00 a.m. She has not slept much in thirty hours, but Shelley Cairo is wide awake. She lifts herself out of bed. Checks on her baby in the incubator. Goes for a stretch. Out in the hall and around the corner, there is an unattended nursing station. A clipboard hangs from the edge of the counter. Her gaze fixes on four words, about halfway down an otherwise white sheet – ‘Baby Cairo DOWN SYNDROME?’

It happened thirty years ago, but Shelley describes the feeling as though it took place three days ago. “I went ballistic. It felt like I had been told my baby was retarded. Or that he was going to be a vegetable for the rest of his life. I was angry at God.” Wavy brown hair flows casually to her shoulders. Her soft green eyes and gentle smile tell you this woman does not easily lose her cool.

Growing up in Kamloops, Shelley had been a tomboy. She rode horses. She was shy and quiet. As a teenager she was awed by the wave of unwashed youth that hitchhiked through the Okanagan in the late 60’s. But what Shelley wanted more than anything was to be a mother. She was 18 when she and Chris married in the 70’s. Then the twins, Tara and Jasmine, were born.

Shelley and Chris were rebels. Dropouts. Idealists. “We were deep into yoga, meditation, spirituality,” she says with a wistful smile. They had tried back-to-the land country living, but had given up after a few years and moved to the big city.

In 1981, when Shelley was pregnant a second time, home births were almost unheard of. For Shelley, nothing could have been more natural. When the baby was born, Shelley remembers thinking the baby looked unusual. Slanted eyes – Asian. But she thought ‘Felicity has eyes like that. And look at the toes. But so and so has toes like that’. Baby looked clunky, like he’d been chopped with an axe instead of cut out with scissors. Beautiful – but the curves of his body seemed square.

Looking back, Shelley says, “My mind was making all these observations but I also saw the truth – maybe he was different, but he was perfectly fine.”

One of the midwives had noticed the yellowish skin, suspected jaundice, and called the doctor. The doctor had taken one quick look at the baby, frowned, and said, “Best to take baby to the hospital.” At VGH, the paediatrician showed Shelley – pointing with a pencil – the Down Syndrome markers on baby’s little body. Shorter body proportions. Flattened nose. Smallish mouth. Squarish face. Short stubby fingers. Straight black hair. And a single transverse crease in each palm. A geneticist told her they would never be able to leave the boy on his own – ever. People with Down Syndrome can have learning disabilities, congenital heart disease, and are at high risk for a whole range of health problems.

Shelley recalls gently lifting her baby out of the incubator, holding him tight to her chest. “I was there with my son, and with God. And I looked into my baby’s eyes and I could tell he wasn’t worried about any of that. He wanted to live. To eat, and breathe, and move around. And I made

a vow right then. Between this God I was mad at, and my son – no matter what any doctor said – I was going to see the best, and do the best for my son.”

They named him Jai (rhymes with ‘my’ and ‘guy’). Victory in Sanskrit. Jai would overcome the limitations of his diagnosis. Down was not going to keep this boy down.

Shelley recalls Chris wouldn't talk about Jai having Down Syndrome. He just didn't believe it. One day, they were listening to the radio when Jai's Infant Development Program worker was giving an interview. She was describing how Shelley had taken Jai for a walk in the forest and showed him how to pick berries, and how that developed his grasp and made his stubby little fingers stronger. That's when Chris turned to Jai with a proud father's grin. “So – you're one of those famous Down kids!” From that moment on, it seemed, Chris became Jai's champion.

In the first year, the Infant Development Program worker came to the house a few times a month to show them how to play with Jai, to help him develop his motor skills. One of the games they played was the Copy-Cat game. Tara and Jasmine would copy Jai's movements. Then he'd see what they were doing and imitate Tara and Jasmine. Or Jai would follow a crayon with his eyes as Tara floated it through the air. Another game was the Hide-Away game. Jasmine or Tara would surreptitiously hide a piece of Lego or some other toy and Jai would scramble, find it, and clasp it in his hand.

When Jai was three and at preschool, the woman in charge had said kids like Jai need to be with their own kind, so Shelley moved Jai to a preschool closer to home. Then Shelley found a day care run by a woman who said she liked to work with special needs kids, but when she saw Jai playing with the pet rat, she abruptly lost interest.

One spring day when Jai was four, Tara announced that she wanted to make a TV commercial to tell the world her baby brother was okay. Shelley thought about creating an educational video for parents with Down Syndrome babies. Too ambitious. But when Shelley's friend Irene shot a series of cool pictures of the whole family just being with Jai, Shelley had another idea. She sat down with the girls and they looked at the pictures. And together they jotted down what they wanted to say about their brother Jai. They chose the best pictures to match their words, and created the children's book *Our Brother Has Down's Syndrome*. (Nowadays we say 'Down Syndrome'.) The book was published by Annick press in 1985. It's still in print. Families look at this little picture book, and they can tell that their Down Syndrome child is okay.

When Jai was in grade two, a friend told Shelley that she had overheard one of his special education teachers say "I hate those DS kids – they're so touchy-feely." When Shelley came by to get Jai one afternoon, he burst into tears the minute he saw her. That teacher had punished Jai for spitting, by demanding he write out 150 lines of 'I will not spit.' Shelley grabbed the paper from Jai's hand, tore it into shreds and threw them at the teacher's feet. "If you want Jai to like writing, why would you choose to punish him this way?"

Shelley found Jai a high school that integrated special kids into regular classes. He got an A in Art. His innate curiosity came alive in science class. And he wrote stories. He would tell his story to a teacher's aide, who would type it up, then Jai would print it out in his own handwriting. One of his stories was about a horse named Quill who caused havoc in the streets of Vancouver. It was published in the community paper. Shelley has a collection of Jai's old stories – over 30 of them.

Jai has tried hard to fit in. After seeing other kids at school smoking outside, he pretended to smoke too. But he never stopped being Jai. He got around by riding his imaginary horse. And he talked to his imaginary friend, George. Sometimes too much George could be a problem, so Shelley asked Jai to spit George out into a jar as he left for school each day. George lived in his mouth.

Shelley and Chris separated. Chris has another family now. Still, he is a big part of Jai's life. He is Jai's hero.

Shelley accepted the challenge of raising Jai as her life's mission, and she was fascinated by the child development aspects. "I've had to fight many dragons – both internally and externally." As a young mother, Shelley had been content just being cloistered at home. Going out had been a challenge. "Then I had this kid who was so different. I knew Jai had to be exposed to the world, and I had to overcome my reclusiveness for his sake."

Shelley is a grandmother, an elder. They recently celebrated Tara's wedding. Jai looked sharp in his black suit and tie. He lives in a shared house, and will soon be moving into his own apartment. Most days he makes his own breakfast. He does his own laundry. But sometimes his dirty clothes don't get further than the laundry basket.

Friday night dinner with Jai is the highlight of Shelley's week. "He cares about people. If someone is talking about their troubles, he says 'life is complicated'. And he has great compassion for disabled people. He says 'Oh, that poor guy'. And he's always telling me I should take it easy."

Shelley's philosophy used to be that good things come to good people. "And now I see that it just is. People and animals are born all sorts of ways. It's up to each one of us to see the special as a tragedy or a gift."