

Different but the same: Vanisha's journey

She was born with a tumour that covered half of her face. Against all odds, surgeons removed the cancer. She faces years of more treatment, but on June 8, she's going to the prom

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OPERATION SMILE

On Friday, May 25, Operation Smile Because We Care will be holding a wine tasting, silent auction, dinner and dance at South Hall Palace, 8273 Ross St., in Vancouver.

Partial proceeds from the event will be donated to the Cleft Palate Craniofacial Program at BC Children's Hospital.

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ABBOTSFORD - Vanisha Dayal is 17 and looking forward to graduating from high school. The big day is June 8, but the bigger day, the prom and the after grad, is the day after.

After months of searching, she finally has a dress -- a turquoise blue gown that her mother, Jaswanti, describes as "a '60s style with lots of ruffles on the skirt." Vanisha's closest friends know what it looks like, but no one else does.

Then there's her hair, nails and makeup.

Getting them right will take time too, but one only graduates from high school once, so like any 17-year-old about to take her first confident steps out of childhood, Vanisha wants everything to be perfect. And if that means spending several hours in the bathroom, so be it.

It's a story familiar to parents of any on-the-verge adult. Grad, the dress, the butterflies-in-the-tummy conflation of nostalgia and expectation. It is one of life's most important rites of passage.

But that's where the familiarity ends. Because as much as she is like her friends and every other excited 17-year-old looking forward to prom night, Vanisha is, in one respect, different.

No doubt a piece of her will cringe if she reads that, but it's true.

When Vanisha was born, she had a tumour that covered half her face. In addition to being horribly disfiguring, it could have killed her.

In fact, after four months of chemotherapy and radiation during which her doctors -- never before faced with a case like hers -- experimented as they went along, Jaswanti and Gulab Dayal were sent home with the euphemistic message to "make her comfortable."



CREDIT: Steve Bosch, Vancouver Sun
Vanisha Dayal, shown with her father Gulab in Abbotsford, was born with a tumour on the left side of her face. She has had her face rebuilt with the help of the charity Operation Smile.

So they did -- and they did such a good job that here she is 17 years later. "She's a miracle," Jaswanti says quietly as we sit down in the family's comfortable Abbotsford home to discuss what happened to her. "That's for sure."

What saved her was craniofacial surgery at Toronto's Hospital for Sick Children when she was four months old. Against all odds, surgeons managed to remove the tumour and, with it, the cancer. (Though Jaswanti cautions that the fear never goes away. "To this day, a little puffiness is a major panic for us," she says.)

But removing the tumour also meant removing much of the left side of Vanisha's face: her eye and its socket, her jaw and her cheek in a marathon 19-hour operation conducted by a team of top-notch surgeons.

For the next nine years, Vanisha grew up having to fly back and forth to Toronto for checkups and various other procedures at the same time she had to confront a world where everyone else looked appreciably different from her.

It's remarkable, but ask her about it, and she'll say she can't remember a time when she was teased or her feelings were badly hurt. In fact, she looks vaguely bored by the question. Maybe she's just being brave -- as her mother says, her private thoughts are her private thoughts -- but Jaswanti also can't recall an instance when Vanisha came home crying because she'd been picked on.

The family puts it down to three things: Vanisha's astonishingly positive attitude -- "she's never questioned why she's different," Jaswanti says -- a highly protective older sister, Jasmine; and to letting school officials, her teachers and, through them, her classmates, know her history before she ever sat down behind a desk.

'Real social butterfly'

Vanisha's current physician, Dr. Douglas Courtemanche, a craniofacial surgeon at the Children's and Women's Health Centre of B.C., attributes it to her upbringing.

"She was always accepted and supported as a person by her parents and by her community," Courtemanche says. "And that's what made the difference. It's the whole social fabric these kids grow up in that's important."

"There's the person who has the facial difference and there's the facial difference itself. They are not synonymous."

He says parents faced with something as difficult as Vanisha's illness and facial difference will do one of two things: treat the child as they would any other, or focus on the difference and risk making the child feel stigmatized.

He says the Dayals did the former, and that's the main reason she is the normal girl she is today.

Or to put it another way: "She was lucky in her choice of parents."

Regardless, the strategy worked. Vanisha always has had lots of friends -- "she's a real social butterfly," Gulab says with a pride and patience any father would recognize. And if anyone is rude enough to ask why she looks different, she just says, "I had cancer when I was born," and that usually is that.

It's also due to another major operation and a series of subsequent procedures she's had in Washington, D.C. beginning when she was nine. The doctor who operated on her when she was a baby reconstructed the left side of her face by taking a bone from her leg and building a new jaw for her.

All the time Vanisha was growing up, the Dayals knew such an operation was coming. Her surgeon, Dr. Jeffrey Posnick, had warned them of it when she was a baby. What they hadn't counted on was that it would take place in the U.S.

As long as Posnick was working out of Toronto, the Medical Services Plan would pay for Vanisha's treatments. But after several years, Posnick relocated to Georgetown University Hospital, and if the Dayals were going to follow him there, they were going to have to pay out of their own pockets.

The problem was that after everything the Dayals had been through, they couldn't conceive of anyone else doing the surgery. Even Vanisha's Canadian oncologist recommended sticking with someone they knew and trusted, and perhaps more important, someone who knew Vanisha.

But hiring Posnick privately was going to cost them \$100,000 US -- an unimaginable sum. It may as well have been a million. They thought about selling their house to raise the money, but back then it wouldn't have been enough. That's when Operation Smile Because We Care stepped in.

Operation Smile Because We Care is a grassroots organization launched in 1998 in B.C. to help children like Vanisha with a disfiguring condition obtain the care they need. In fact, Vanisha was the first child the group helped.

It seeks to provide such children with financial support where medical funding may be limited or unavailable.

It also helps the entire cleft palate and craniofacial department at Children's Hospital, and the more than 1,600 children it serves, Courtemanche says, by providing funding for equipment, education and patient care.

And every year, some of what it raises helps send children like Vanisha to camp, where they can spend a week in the company of other kids with the same problems and in doing so, know they're not alone.

As well, Vanisha's schoolmates raised money for her travel and operation, as did the local fire department and various businesses. She was featured on the news so even more people knew about her, and more money came in.

Going to nursing school

It was all very much needed and appreciated, but it also was tough on the Dayals. As grateful as they were for so much kindness, it was hard for them to be seen with their hands out. Gulab mimics someone with a begging bowl as he says, "We didn't want people to see us like this."

But it was the only way, they recognized. And because of it, Vanisha can now look forward to going to nursing school this autumn.

Not that she's out of the woods yet. While Posnick was able to reconstruct her face, he wasn't able to give her a jaw that worked. Instead, the left side of her face is fused to the point that she can't really move it. That makes chewing difficult, and if she were to choke, there's nothing anyone could do for her.

Also, the patch over what was her left eye was taken from flesh on her abdomen, and over time that patch has grown to protrude more than Courtemanche or the family would like.

So they hope that some time before the end of this year and next, Vanisha, who is now old enough to undergo such procedures, will be able to have further surgeries to correct that immobile jaw and, Courtemanche, hopes, to have her eye patch replaced with something less obvious, perhaps even a glass eye prosthetic.

This time, the operations will be in B.C., so they will be covered under MSP.

On May 25, Operation Smile Because We Care is having a fundraising gala, and because of that, it asked the Dayals to allow Vanisha to tell her story again.

The family has obliged, but the result is that the same confusion of emotions that arose eight years ago is at work again. "Gulab was all for it, but I wasn't so sure," Jaswanti admits.

On the one hand, they're tremendously thankful for everything Operation Smile Because We Care did for Vanisha, and they recognize that by telling others about its work, it may be able to help other kids like her.

"There could be other families in similar situations, and we want to help them," Gulab says with real concern in his voice.

But on the other, it's hard for them to set Vanisha up again as a kind of poster child. Because despite everything's she's been through, she's nothing of the kind. What she is, is another young woman about to step boldly into a new, exciting and maybe even slightly frightening adventure in a turquoise blue evening gown with ruffles on the skirt.

In that way she is no more -- or less -- extraordinary than anyone else her age.

All it takes to recognize it is to look at her. It's as plain as the smile on her face.

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