

# Whyte-Croasdaile wants to help others like her through support group

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High confirmed it was SJS/TEN and treatment commenced, most of it consisting of treatment for burns that a burn patient would undergo. She couldn't eat, since her internal organs were just as badly burned as her outer skin, so she was fed through a tube for many weeks.

She was transferred to Hamilton General Hospital for burn treatment for a few weeks and also taken to Oakville Trafalgar Memorial Hospital for eye treatment. Because her eyes were so severely affected, doctors were concerned she could become blind. They were burned closed and even her eyelashes fell out.

She couldn't stand to have clothing brushing her skin and wore children's clothing inside out so the seams didn't irritate her skin.

Her husband, who spent nearly ever moment at her bedside, said it was just as well her eyes were closed because Whyte-Croasdaile would not have wanted to see herself like that.

"She didn't have to see people's reactions to seeing her," he said. "It was the most horrendous illness."

As a nurse herself who worked with Red Cross Society prior to the illness, Whyte-Croasdaile said she's familiar enough with nursing to know that MDH went above and beyond.



Whyte-Croasdaile was barely recognizable to friends and family while she was being treated for Toxic Epidermal Necrolysis.

From the beginning, when she had difficulty swallowing liquid Tylenol for pain relief, she knew she was in good hands.

"A nurse, came and held my hand...she calmed me down," said the mother of two who's called Milton home for several years. "She told me to imagine it was a cocktail. I did and it worked."

She added that because of her case, MDH is a part of history — becoming the first local hospital to treat a known case of SJS/TEN.

After she finally returned home, six weeks after the grueling experience, the Jamaican-born Whyte-Croasdaile's life slowly returned to some normalcy. But her energy never returned to where it once was. She sought answers and she also wanted to help others who she knew would be facing a lonely road ahead once diagnosed with the illness.

She stumbled on Sunnybrook Health Sciences Center, dermatology department where they've helped give her some guidance to

the rare illness that affects only one to six people per million each year. Risk of return is high since there's no proven treatment. She also doesn't know what caused it and may never know.

"It could be genetic, it could be a reaction to a medication, or it could be viral," she said. Sunnybrook is a main treatment site for SJS/TEN in Canada. There she found some hope and some answers, but still not enough she said.

To that end, she created the Canadians Against Stevens-Johnson Syndrome and TEN (CAST), which provides online assistance to people and families who have been diagnosed with the condition.

She's hopeful the support group will provide others who find themselves in her position — lots of questions and little hope — with answers, hope and education.

"I want people to be aware of this monstrous thing that's out there," she said.

Whyte-Croasdaile can be contacted at [sjsandtensgroupcanada@gmail.com](mailto:sjsandtensgroupcanada@gmail.com) or via facebook at [www.facebook.com/SJSandTENSCanada](http://www.facebook.com/SJSandTENSCanada).

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