

Family lives to make a difference, build memories

Laura Lennie, News Staff

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When a family gets a cancer diagnosis it's never easy.

No one knows that better than the Williams family.

Avery Williams was diagnosed at three months old with bilateral retinoblastoma, a cancer that affects about one child in 15,000, with about 23 children affected in Canada each year. Without early detection and appropriate treatment, retinoblastoma is almost always fatal.

Avery has endured cycles of chemotherapy, laser and cryo therapies to fight several tumours in both her eyes. In 2001, she was diagnosed with permanent, bilateral, high frequency hearing loss, a side effect of the chemotherapy. Later that year, to prevent the cancer in her left eye from spreading into her brain, her eye was removed and Avery was fitted with a prosthetic eye.

Her 'good eye' has permanent blind spots and she can only read one line of writing at a time. She misses high frequency sounds, so sometimes can only catch part of her teacher's instructions.

But she has two intervenors, who assist her to make sure she gets all the information in school. Avery, her intervenors and teachers also use FM hearing aids, so she can hear them more clearly. Her computer uses larger fonts and has a larger keyboard and Avery's larger calculator is "super cool because it talks."

Avery's mother, Ericka Dixon-Williams and father, Junior started Avery's Journey in October 2001 to raise awareness and generate funds for Avery's education plan and for retinoblastoma research at Sick Kid's hospital.

"When Avery was diagnosed, the part that really baffled me was I knew nothing of bilateral retinoblastoma," said Ms. Dixon-Williams. "Eleven years ago when you typed in the words on the Internet, one paragraph came up. I thought, 'This can't be; I have to do something, I have to get the awareness out there,' because, as with all cancers, early detection is key."

Since then, they have raised \$12,000 for Avery's education plan and \$28,000 for the Hospital for Sick Children Foundation for Retinoblastoma Cancer Research.

On Friday, May 1, an Avery's Journey, Celebration of Life Dance will be held at Renaissance Banquet Centre to raise funds for Avery's education plan, the Canadian Deafblind and Rubella Association and Camp Trillium. The event will include a buffet dinner, dancing, door prizes and a performance by members of Star-Lite Dance Studio.

"It's an important event because it's helping other kids who have cancer or have something that I had, when I was young," said 11-year-old Avery, adding Camp Trillium holds a special place in her heart. "Camp Trillium is the best place on earth. It's a place, where you don't have to worry about prosthetic eyes and hearing aids; it makes you feel like you fit in because there's other people just like you there."

Avery visits the ocularist three times a year to get her prosthetic eye cleaned and checked and every two years, she gets a new eye. She has annual checkups at the Hospital for Sick Children in Toronto and visits her audiologist twice a year.

In her spare time, she likes to play volleyball, but really loves to sing and dance.

"When I sing, I sing old-fashioned songs like Aretha Franklin," she laughed. "I like to dance a lot too."

When asked how she feels about everything she's gone through, Avery smiles.



Avery Williams was diagnosed at three months old with bilateral retinoblastoma. Her parents started Avery's Journey in October 2001 to raise awareness and generate funds for Avery's education plan and for retinoblastoma research at Sick Kid's hospital. Pictured, left to right, are Avery, sister Savoy, mother Ericka Dixon-Williams and father Junior.

"I've heard a lot of stuff about when I was young, but I honestly don't remember any of it," she said. "It's like they're talking about another person."

Ms. Dixon-Williams certainly remembers. "Very often, Avery catches me just looking at

her and she'll say, 'Mom, what are you looking at?' And she'll say, 'I know, I know, the big C.' But I look at her and she's simply amazing. She never gives up. She gives us strength to do all that we do."

Ms. Dixon-Williams says she gets nervous when she zones in on the details.

"The teenage years could be challenging. Your cells become more active as the body grows and if one RB gene is affected, she will get cancer. That's quite scary," she said. "Day in and day out, we try to live each moment, build memories, try not to take anything for granted and just enjoy her...living with no regrets is the key."

The Avery's Journey Celebration of Life Dance fundraiser supporting Avery's education plan, the Canadian Deafblind and Rubella Association and Camp Trillium will take place Friday, May 1 from 7 p. m. to 1 a. m. at Renaissance Banquet Centre, 2289 Barton St. E. Tickets are \$25 (Mastercard and Visa accepted). Advance ticket sales only. For tickets or to make a donation, call Ms. Dixon-Williams at 289-260-2297 or 905- For more information on Avery's Journey, visit www.averysjourney.ca .

How to spot signs of retinoblastoma

Retinoblastoma is a rare childhood eye cancer that primarily affects children under age seven.

Without early detection and appropriate treatment, it is almost always fatal.

Retinoblastoma is hard to detect. The critical clue is the glimpse of a "white pupil" in a child's eye or a white/yellowish pupil in a photograph.

For more information, visit www.rbsociety.ca .

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