

# CITY LIFE

City Life Editor - **Vikki Hopes** • General inquiries: 604-853-1144 • Direct line: 604-851-4530 • editor@abbynews.com

## Mom lives with rare genetic condition

by **VIKKI HOPES**  
Abbotsford News

Julie Drybrough is cuddling her four-month-old daughter – her third-born child – when she coughs.

The otherwise-normal action sends searing pain through her head. Julie has been having progressively worse headaches since her daughter's birth, but now the pain is so intense that she almost drops her baby.

It's time to have her symptoms checked out. What she doesn't expect to hear, after the appropriate medical tests are conducted, is that she is suffering from the hereditary condition that, years before, she was ruled out as having.

Julie is told she has a benign tumour on her brain and that a fist-sized cyst has grown around it.

The symptoms are all-too-familiar: Her grandmother, mother and an uncle had all experienced tumour growth – the result of a rare genetic illness called Von Hippel-Lindau (VHL) syndrome. In their case, the condition was fatal, as malignant tumours developed on their kidneys.

It is soon confirmed that Julie has inherited the condition. The news couldn't come as more of a shock.

Her family never talked much about the disease that had ravaged them, but Julie grew up knowing its devastation. She had been told that her mom, Darlene, first displayed symptoms at the age of 12, when she developed eye tumours.

By the age of 38, Darlene developed malignant tumours in her kidneys and had both of them removed. About 10 months later, she required brain surgery.

Julie was 16 at the time of her mom's kidney surgery, and she



JOHN VAN PUTTEN / The Abbotsford News

Julie Drybrough relaxes with her daughters (from left) Samantha, Trinity and Katarina. She wants to increase awareness about a rare condition called Von Hippel-Lindau, with which she was diagnosed in 2005.

became pregnant with her first daughter, Samantha, who turns 11 next week. Julie had never displayed any symptoms of VHL but her parents were worried that she might have it or that she would pass it on to any children she might have.

Her teen pregnancy meant they had to face the situation earlier than they had expected. A test, called "linkage analysis," was conducted, and Julie was told she did not have the condition nor was she a carrier. In a horrible twist of events, she later discovered that the test is unreliable.

Darlene endured nine years of dialysis before dying on Sept. 11, 2004 ago at the age of 46. At the time of her death, the kidney cancer had spread to her lungs.

Darlene's mother had died at 49 and a brother perished at 29.

It is 2005 when Julie is told she could face the same fate, except that

things are different with her:

Her years of watching her mother suffer means Julie has learned much about the condition. One thing she has learned is that immediate and ongoing treatment is crucial. Her family had difficulty dealing with the issues surrounding their illness, and treatment was not sought as readily as it could have been.

Julie decides she will take a proactive approach, backed by the support of her husband Chris, whom she has been with for eight years. He is adamant that VHL "is not a death sentence."

But the diagnosis brings a heavy burden for the couple. "The first thing that came to my mind was, 'Oh my God, I've given it to my girls,'" Julie says.

Believing that Julie did not have the condition, the couple had two children together – Katarina, now 6, and Trinity, 22 months. (Samantha

was born before Julie met Chris.)

But before tests can be conducted, Julie must undergo brain surgery to remove the tumour. This takes place on Jan. 5, 2006, and it takes about four months for her to recover from the procedure and the complications that follow.

At this time, testing is more precise than it was when Julie was told she did not have VHL. All three daughters test positive for the condition.

The couple are devastated by the news, but vow to stay positive and do everything they can to educate their daughters and ensure they live long happy lives.

"You hope things change," Julie says of medical advancements that could lead to a cure.

Chris reassures her: "Don't hope. It *will* change."

Julie has just now recovered from her last procedure – the removal four months ago of a por-

tion of her left kidney, which had developed a cancerous tumour.

She is currently being monitored for tumours on her brain – she had two that seem to have disappeared – and one on her spine, but she doesn't dwell on the repercussions.

"Pretty much now, when something pops up, it gets taken out," she laughs.

Julie wants to break the code of silence surrounding the condition and dispense of myths – such as that VHL is a "rage disease," as suggested in recent media reports. "This disease does not make you rage. People make themselves rage," she says.

Her own family's silence about VHL has already been broken. Samantha recently competed in a French immersion speech contest in which she talked about the condition.

She reached the semi-finals.

### VHL causes tumours

**Von Hippel-Lindau syndrome results from a mutation in chromosome three, which normally prevents tumour growth.**

**In those with VHL, tumours can grow in the central nervous system, retinas, adrenal glands and kidneys.**

**Most tumours are benign, but those found in the kidneys are malignant.**

**Untreated, VHL can result in serious repercussions, such as blindness or brain damage. Those who die from the condition usually experience complications from kidney cancer or brain tumours.**

## Dishonest deed brings deep embarrassment

"Wanda, two police officers are leading your mother through the mall. They just came out of Buchanan's bookstore."

"Is she OK? Did she fall?"

"I don't know. She's pulling her little oxygen cart and seems to be dragging her feet. You better get down here."

Wanda Patton thanks her cosmetician for calling and runs to her car in the parking lot of the accounting firm where she works.

She thinks, "Why didn't they call an ambulance? Maybe she's having a heart attack."

Wanda rushes into the bookstore. There's a line-up at the cash register. She interrupts a clerk taking a customer's payment.

"What happened to my mother, the older lady with the oxygen cart?"

The clerk motions for

Wanda to wait. She lowers her voice.

"I'll be with you in a moment. Your mother had a little mishap."

"What kind of mishap?"

Wanda raises her voice.

The clerk's eyes begin to smoulder: "Can't you see I'm helping a customer?"

Wanda won't move.

"What happened to my mother? Where is she?"

The clerk throws up her hands.

"Well, if you want everyone to know, your mother was arrested for shoplifting. She stole *The Grapes of Wrath* hardcover right off the front table."

"Stole? She's a 75-year-old great-grandmother. Why would she steal a book?"

"She stole it, all right. Browsed around the store with it in her hand for half an hour, then stashed it in



**ALLEN UNRAU**  
Young and Old Alike



the tank bag of her little cart. Security caught everything on video, and she was detained the second she stepped into the mall."

"You called the police on an old lady with an oxygen tank?"

"It's our policy, ma'am. No exceptions. We prosecute all shoplifters to the full extent

of the law."

Wanda is embarrassed. For some time, she's been afraid her mother's been losing it. Ruth hasn't been the same since her husband Herb died two years ago.

At the police station, Wanda rushes up to the enquiry desk. "Are you holding a Mrs. McCormick here?"

"Yes. Are you a relative?"

"I'm her daughter. I must see her immediately."

Ruth is sitting on a grey steel chair with her chin sagging against her ivory wool sweater.

Wanda kneels in front of her. "Mother, did you take the book?"

Ruth nods.

"Why?"

"Because it's your father's favourite book, dear. I wanted a new hardcover for him, and there never seems to be enough money from our pen-

sion cheques."

Wanda turns to the police officer:

"My mother is a little confused these days. She didn't know what she was doing. Can I just pay for the book? I'm sure this won't happen again."

The officer frowns.

"I'm afraid not. The store insisted on laying charges. We can't just let her go."

Unexpectedly, Ruth joins their conversation. "Why not? You policemen did it when Wanda stole that fold-up stroller for baby Joel."

"What?" Wanda is reeling. For 30 years, she has kept quiet about her desperate act as a very young mother with a new baby and no extra money.

She still shudders when she remembers being arrested and taken to the police station. She couldn't be-

lieve it when, out of the blue, someone paid the store and the officer said she could go without being charged.

Wanda stares open-mouthed at her mother:

"You knew?"

Ruth takes her daughter's hand.

"A friend of mine who worked in the mall saw the police take you, dear. She paid for the stroller, and I paid her back over the next three months out of my egg money."

Wanda gasps. "My greatest fear all these years was that you'd find out. Why didn't you say something?"

"You were a wonderful mother, Wanda. I knew it wouldn't happen again."

*Allen Unrau's columns are fictional stories about real-life issues. Comments? allenunrau@yourlifeweekly.com*

### Slice of Life

#### Picnic for volunteers

The local Big Brothers Big Sisters agency holds a volunteer appreciation picnic today at the Fraser Valley Trout Hatchery.

Abbotsford "Bigs" and "Littles" meet from 9 a.m. to noon, and Mission and Maple Ridge matches get together from 1 p.m. to 4 p.m. A barbecue is held at noon for all groups.

For more information about the agency or on becoming a volunteer, call 604-852-3331 or visit [www.mentoringworks.ca](http://www.mentoringworks.ca).

#### Time for Spring Fling

The Valley Women's Network holds its 19th annual Spring Fling on Wednesday, April 25 at the Ramada Plaza and Conference Centre.

The evening features live entertainment, a casino, shopping, a fashion show, dinner and chances to win prizes.

Doors open at 5 p.m. For tickets, call Peggy at 604-854-5640 or e-mail [peggyallen@shaw.ca](mailto:peggyallen@shaw.ca).

#### Story times at library

Matsqui Centennial Library (33660 South Fraser Way) holds a new series of story time sessions, starting next week.

Terrific Twos runs Tuesdays at 10:30 a.m., from April 24 to May 15.

Thrilling Threes to Fives is on Wednesdays, also at 10:30, from April 25 to May 16.

Registration is not required. Call 604-853-1753 for more details.

#### Taste of culture

The Scandinavian Club of the Fraser Valley holds its monthly pot-luck dinner on Monday, April 23.

The event begins at 6 p.m. at the Eagles Hall (33868 Essendene Ave.).

For more information, call Ken at 604-859-3996, Eigel at 604-870-8601 or e-mail [jen-senke@shaw.ca](mailto:jen-senke@shaw.ca).

#### For retired workers

The Fraser Valley branch of the B.C. Government Retired Employees Association holds its monthly meeting on Monday, April 22 at 1:30 p.m.

Location is the Seniors' Resource Centre (2478 McCallum Rd.). Speaker Dan Traylor from Homestead Nursery discusses gardening.

For more information, call Kay at 604-859-4492 or Norma at 604-855-9972.

#### Support for families

A support group for the family and friends of people with schizophrenia or other mental illness meets Tuesday, April 24.

The group gets together at 7:30 p.m. at the B.C. Schizophrenia Society office (2615 A Montrose Ave.). Call 604-859-0105 for more information.