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THE EXPOSITOR

Brantford Expositor (ON)

Showcase, Thursday, October 12, 2006, p. C1

A family's fight

Candid memoir follows two Brantford sisters as one is ravaged by cystic fibrosis

Elizabeth Yates

Brantford - Lungs clogged with blood and mucus but fierce in her deathbed determination, Pam Summerhayes gasped out a demand for her sister to write the remarkable story of how cystic fibrosis affected their lives.

Finally, more than two decades later, Heather Summerhayes Cariou has chronicled their relationship in a compelling new memoir called SixtyfiveRoses. Its title taken from Pam's childhood name for the incurable disease, the book is touching, insightful and unflinchingly honest.

While the story of the Brantford sisters is gripping, SixtyfiveRoses offers far more than a personal biography.

It is as valuable for readers who have not been touched by devastating illness as for those whose experiences may parallel the Summerhayes' torturous and beautiful journey.

"This is not a book about cystic fibrosis," Cariou emphasizes during a telephone interview from home in New Jersey. "This is a book about a family struggling with an illness in their midst.

"Pam said, 'Tell our story.' To me, the story is in the difficulty of a family like ours ... Where there is any kind of catastrophic or long-term illness, there is a lot of anger, there is a lot of anguish.

"And it's unspeakable: you don't want to burden your friends or your other family with it. So there's a really strong sense of isolation."

Families without these pressures should know what their neighbours are going through, says Cariou. "I'm hoping this book will be illuminating, I'm hoping it will be healing."

Above all, she hopes it expresses Pam's own inspiring attitude: "that life is worth any struggle, that joy can be found in any moment and that it's important not to give up."

Rich with lively detail, SixtyfiveRoses explores the uncannily close relationship between Heather, the eldest, and Pam, born 22 months later. Though at times fighting like wildcats - both physically and verbally - the two shared a Herculean bond that just intensified when the younger girl was diagnosed with cystic fibrosis at age four.

In the 1950s, little was known about the genetic condition, which attacks the respiratory and digestive systems so that lungs fill with mucus and food isn't properly digested.

The lack of resources left parents Douglas and Donna Summerhayes struggling to care for Pam, Heather and their younger boys, Gregg and Jeff, who also has CF. Determined to do the best for their sick kids - and to help other families facing the same hurdles - the Summerhayes founded the Canadian Cystic Fibrosis

Foundation. Later honoured for their dedication with the Order of Canada, the parents were sometimes stretched thin by their work with the foundation, nursing Pam and Jeff, and, in Douglas's case, weathering uncertainties in the business world.

All these pressures created rifts which Cariou candidly explores, emphasizing that SixtyfiveRoses is her own memory of those years before Pam died at age 26.

While her parents' recollections may differ, they urged her to write her own truth, not holding anything back on their account.

"That really liberated me and liberated my writing in ways that has made my final manuscript a success.

"As far as I'm concerned," she adds, "my parents are my absolute heroes. I love them very much and I'm very proud to be their daughter."

Published in Canada by McArthur and Company, the book is pleasing readers so far. After Cariou appeared at the Winnipeg Writers' Festival in September, SixtyfiveRoses shot to No. 2 on the bestsellers' list at Manitoba's McNally Robinson Booksellers. "I got a really warm response from the audience, so I'm quite encouraged," says the author, who's donating some proceeds to the cystic fibrosis foundation and has an endorsement from Celine Dion, celebrity patron of the charity.



She embarks on a book tour in October and November to several Ontario cities including Toronto and Ottawa as well as Calgary, Montreal, Edmonton, Vancouver and Victoria. She'll be in Brantford on Oct. 19-20 to speak to the Kiwanis and Rotary Clubs and, on Nov. 29, at Paris District High School. And other bookings are welcome.

"I'll appear anywhere," Cariou enthuses. "I'll come to your living room and talk to your book club."

Some 20 years of research, self-discovery and endless rewrites went into the 376 pages of *SixtyfiveRoses*, which are accented by dozens of family photos.

Begun a few years after Pam's death, it first took form as a personal journal. Then Cariou - a longtime stage actress - began a serious study of her new vocation, taking workshops and classes, reading numerous memoirs and, most importantly, joining the International Women's Writing Guild, an invaluable source of support and information.

"Mostly what I did was I wrote and I wrote and I wrote," says the 54-year-old, who jokes that the book "took half my life to live and half my life to write."

At times, though, the pain dredged up on paper forced her to take a break and get some therapy. "Once I started writing it and looking at it from all the different angles, a lot of new emotions came up."

Finally, three years ago, a final draft was ready. Cariou secured an agent, who eventually sent the manuscript to Toronto's McArthur and Company - owned, kismetically enough, by another Brantford native, Kim

McArthur. "We had a deal within two weeks. I think it was meant to be."

The finished product is being proudly promoted in Brantford by Donna and Doug, who aims to sell a book a day. Gregg, a Brant County OPP officer, has been handing out his sister's business cards. Jeff is also happy, says Cariou, noting he shares Pam's fighting spirit. Left with about 50 per cent lung capacity, the 44-year-old lives in Paris and works as a river guide. "He's quite determined."

Pride, though, mingles with other feelings for their parents, who have had long, intense conversations since the book stirred up some dormant issues.

"The last couple of weeks have been very emotional," says Donna, 73. Doug, 76, says perhaps *Sixtyfive* is a tad too candid.

But both laud Heather's skill at weaving together a story that so ably conveys Pam's determination to "never, ever give up."

With a forceful spirit that overrode her physical frailty, the feisty young woman managed to survive countless hospitalizations and earn a college degree, later opening a preschool in Brantford with two partners.

She was, says her sister, "someone to be reckoned with."

"Pam wasn't an angel and nor was I. But the beauty of our relationship was that it ran the gamut. And, by the time she died, nothing had been left unsaid between us."

Still, the loss was visceral for Cariou, whose first marriage broke up a few months later.

That turmoil was followed by joy as she met "the love of my life," celebrated Canadian actor Len Cariou. They moved from Stratford to New York City in 1983 and married in 1986. Having relocated to New Jersey seven years ago, the couple now enjoy a heartstopping view of Manhattan across the Hudson River.

Though she loves performing, Cariou has been on a sabbatical for the past decade, busy writing and helping Len with his career. Now 60-ish, the prolific stage, movie and TV actor has most recently appeared in the feature films *Boynton Beach Club* and *Flags of our Fathers*, as well as the Showtime TV series, *Brotherhood*.

Travel is a constant for the couple, says the new author, who is now working on a fictional novel about family betrayal.

In the meantime, while waiting for more readers' reactions to *SixtyfiveRoses*, she's certain its heroine would be happy.

"I think Pam's just dancing right now," Cariou says, the grin on her face evident across a long-distance line. "I think she'd be thrilled that I accomplished it and found what I was meant to do."

"She knew me better than anybody and she always thought I was meant to be a writer. When I was acting, I think she always thought I was off on a bit of a tangent."

Boxe(s):

Sixtyfive roses

- Who: City native Heather Summerhayes Cariou, whose new book, *SixtyfiveRoses*, chronicles her sister Pam's life with cystic fibrosis.

- When: Oct. 19, 10 a.m. - guest speaker at Kiwanis Club of Brantford, Beckett Building
- Oct. 20, 12 p.m. - guest speaker at Brantford Rotary Club, Brantford Golf and Country Club
- Cariou is available for other appearances: contact Janet Harron, VP Publicity McArthur & Co., 416-408-4007 ext. 25; e-mail janeth@mcArthur-co.com
- Also: check www.sixtyfiverosesthebook.com

Figure:

Pam poses for The Expositor with a new medical apparatus, a tent exuding medicated mist meant to ease the choking associated with cystic fibrosis.

Big sister Heather poses with her toddler sister Pam, long before her racking cough and inability to gain weight were diagnosed as symptoms of cystic fibrosis.

Heather Summerhayes Cariou

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