

AMBER

## Her daughter's ordeal still has special meaning

By CINDY SIMONEAU Sunday Post staff writer

SHELTON — Like most proud mothers, Patti Calistro Stiewing of River Road wanted her daughter to be famous. Little did Mrs. Stiewing know when she made that secret wish more than four years ago that her daughter Amber's claim to fame would come through death.

"I was trying to get her established as a child model. She was so pretty with those big beautiful blue eyes and brunette hair that I knew she could easily make it as a model," said Mrs. Stiewing. The 29-year-old mother now recalls that she had barely launched her daughter's promising career when it was interrupted, and eventually shelved, due to the discovery that Amber was suffering from cancer.

AT FIRST IT seemed unfair to Mrs. Stiewing that her daughter, at the immodent age of 3 1/2, had contracted what was later diagnosed as rhabdomysarcoma, a cancer affecting muscles. Now, more than two year after Amber's death at age 4 1/2, Mrs. Stiewing feels that her daughter's ordeal had special meaning.

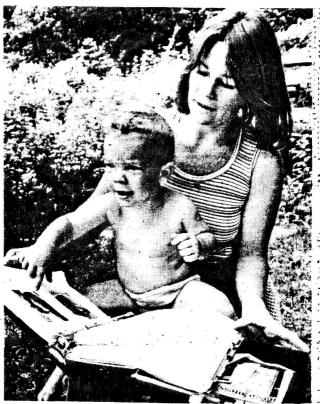
"Before she died, even Amber knew she was going to help a lot of people by her suffering," she said. Mrs. Stiewing is now attempting to fulfill that wish by publishing a book about their experience of dealing with cancer, and more importantly, with the "politics" of doctors who treat cancer victims. She is hoping to develop an audio-visual program to help families and children deal with cancer.

From the first day that a tumor was discovered on the back of Amber's bead, to the last moments of the young girl's life and the months after her death, Mrs. Stiewing has carefully recorded and documented everything the two encountered.

"I'VE USED MY journal, tape recordings, photographs, medical reports and correspondence along with numerous volumes of information to put the book together," said Mrs. Stiewing, who finished the first draft recently.

Dedicated to Amber, "her life, her death, and the footprints she left behind," Mrs. Stiewing has taken a stark approach, including numerous upclose photos of Amber's tumor and the girt while she was dying. The book is tentatively entitled "The Story of Amber," and Mrs. Stiewing is meeting with friends to edit the draft, and is seeking a publisher

(See ORDEAL, CL)



MOTHER AND SON — Patti Calistro Stiewing and son Toby leaf through Mrs. Stiewing's book on her daughter's ordeal with cancer. (Sunday Post photo by Henry Roman)

## Ordeal still has meaning

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for the volume.

One of the difficulties which Mrs. Stiewing says she first had to overcome was the attitude of doctors stating that there was nothing wrong with her child.

"Here I had found a tumor behind her ear, and doctors, many of whom are respected members of their profession, were trying to make me believe there was nothing wrong. One well-known doctor in this area actually wanted me to believe it was an abnormal bone growth that she would probably outgrow. Can you believe it?" said Mrs. Stiewing.

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According to Mrs. Stiewing, it took six months for her to finally convince doctors that something was actually wrong with her daughter. "It was about that time when she hit her head on the fireplace, and the tumor doubled in size. We tried all sorts of treatments and therapies and nothing seemed to help," she recalled. When the tumor developed and therapies appeared to stop working, doctors operated to remove the growth.

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"It was a rapidly growing cancer.
Shortly after the operation a second tumor grew in the same spet. I tried everything to get help for her, even public appeals, but finally I decided to take her to the Grand Bahamas to get treatment from Dr. Lawrence Burton, "she said. Burton, an immunotherapist, tried several treatments which halted the tumor growth.

"YOU COULD actually see her condition improving. But eventually it was apparent that Amber was going to need another operation. Doctors in the United States didn't want anything to do with Amber then because she had dropped out of their conventional treatments. Dr. Burton was so helpful, he actually paid for us to fly to Canada to see doctors there about he operation. By then, though, it was too late. So we came back here to be with seath other."

late. So we came back here to be with each other," said Mrs. Stiewing.

Doctors, said Mrs. Stiewing, could accomplish a great deal if they worked together to conquer cancer. "Everyone has friends and relatives dying of cancer around them. I think doctors, if they would just forget the politics, and not try to just push their single form of therapy on patients, more people would live," she said.

Throughout the ordeal, Amber, according to her mother, did not suffer pain until the last few months. "I was so thankful that God spared her from that

pain," she added.

Now that she has completed the book, Mrs. Stiewing said she feels as if a weight has been lifted off her shoulders. But not until it is published and in bookstores will she mourn the loss of her daughter.

"I can't explain what drove me to finish this massive book. It's something I had to accomplish for Amber's sake. Once it's complete I'll probably go somewhere and have a good cry," she said.

UNTIL THEN, she is enjoying life with her husband Gary, and sons Todd, 7, and Toby, 14 months. "I wonder if the same thing could happen to Toby. There's no guarantee, I suppose, that it won't. I hope it doesn't, but if it did I'd know this time who to believe and who not to," she said.

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Mrs. Stiewing said she hopes the book will help families who are now dealing with the same difficulties. "Amber wanted to hlep other children, and through this I think she will," said Mrs.