

Amber's Story ...Life & Death

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Bernard Siegel, surgeon — *"She seemed more like 400 (years old). She was so wise. Whenever I sent her for X-rays or tests, everyone came back to me saying, 'She's so beautiful... so cooperative.' She made people feel good around her."*

Amber Calistro died Oct. 30, 1980, after a 15-month battle with a rare cancer called rhabdomyosarcoma.

Patricia Calistro Stiewing "always suspected something" tragic would happen in her little girl's life. She documented her actions, comments, took movies, and saved the child's drawings.

As Amber struggled for life, and finally an escape from it, Patti vowed she would write a book. She has believed all along that Amber was "a messenger from God and I want her to communicate her message to others."

The first draft has been put together with quotes, at Patti's request, from those who touched and were touched by Amber's experience. Fan mail, photos of the child's life including her last moments, her death and her ashes chronicle Amber's existence. Some excerpts from the book, and a quote from Dr. Bernard Siegel, and friend Arla Amara have been included here for Milford Citizen readers.

Arla Amara, worked with Dr. Lawrence Burton, at the Immunology Researching Centre, in the Bahamas, where Amber was treated — *"Dear Amber, I think that what you make me think about is that you have proven that a person doesn't have to be big to be courageous; and a person doesn't have to be big to be strong. Love has to be big, though, and big love can come in very little people. Big love, Arla."*

Throughout Amber's battle with cancer, Patti had been concerned about other families with dying children. Conventional treatment — radiation and chemotherapy — disillusioned the young mother, so she opted for the Burton clinic. The treatment was successful until Amber contracted tonsillitis. "Then the tumor got ahead of the treatment," Patti said; so they came back to the United States to seek a surgeon who would remove the tumor which had begun ballooning behind the child's right ear. Medical diagnoses revealed surgery would not improve the situation, so Patti and Amber prepared for the inevitable with the assistance of Siegel, a New Haven doctor who offers guidance in a peaceful approach to life and death.

The book is dedicated: "for Amber — her life, her death, and the footprints she left behind." Noted author of 'On Death and Dying,' Elisabeth Kubler-Ross has offered assistance with the book which is expected to be completed by August. It is divided into four parts: Birth - Discovering the lump; Surgery - Therapy in the Bahamas; Return to U.S. - Her death; Since her death.

Patti's outrage at the bureaucratic foot dragging among politicians, pharmacists, and doctors continues to boil. "They keep fighting among themselves, instead of getting together for one purpose — to cure cancer," she said. The 29-year-old's efforts have been centered on cutting through the politics and working toward allowing people to seek the treatment of their choice to combat disease. She hopes the funds from her book sales will be adequate to start a foundation to assist others with problems.

Another goal is to create an audio-visual program on life and death based on Amber's struggle.

Patti has a new baby. She and Gary Stiewing, who shared the pain through Amber's battle, have a 14-month-old son, Tobias (Toby). They left Milford to live in Shelton where Patti continues her work as a graphic artist and Gary works as a shipbuilder.

They plan to move onto Seawing, their 35-foot sloop, within six weeks. In the fall they will sail to St. Croix.

Some weeks before Amber died she told her mom, "I know I'm here to help a lot of people."

As Patti explains within the purpose of her book, she won't harbor the "pain and suffering," nor will she deny that it exists within others. "I must hold true to my beliefs — That God will protect me from the world. Whatever hardship and suffering I will endure, will be like a drop in the ocean. Amber is that ocean."

The story of Amber and Patti takes its readers on a voyage through time — from the moment the native Californian met Michael Calistro, the man she wanted to father a child with her, through the agony and ecstasy of being poor, frightened, loved, loving, angry, confused, altruistic, and determined.

Patti Calistro Stiewing tells it all, with purpose for a purpose. She, too, feels — and knows — she's here to help a lot of people.