

Family Living

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THURSDAY
Feb. 1, 1996

Patti Stiewing holds a portrait of her daughter, Amber, who died of cancer 15 years ago at the age of 4. Amber was holding the key in the foreground — a symbolic key to heaven Ms. Stiewing had given her — when she died.



By David W. Trozzo — The Capital

For
the
love
of

Amber

One mother's quest to give cancer an identity

By MARY GRACE GALLAGHER
Staff Writer

As her 4-year-old daughter's battle with cancer was winding down, Patti Stiewing's struggle was just beginning.

Promising herself that Amber's ordeal would somehow change the world, Ms. Stiewing took pictures of the bulbous tumor that had overtaken her child's neck and audiotaped the unexpected wisdom of her dying preschooler.

Now, 15 years after Amber's death, the Davidsonville resident is preparing to self-publish "Amber's Legacy." In it, she gives cancer a face — "the face of an angel," said Ms. Stiewing, 42.

That face, with its watery blue eyes and delicate arched lips smiling gently on the Veloxed book cover, is a pinker, younger version of Ms. Stiewing's own. "Cancer is overwhelming," said Ms.

Stiewing, who just moved back to the area with her son after spending two years in Florida. The statistics showing cancer to be the No. 1 cause of death by disease for children under age 15 are especially daunting. That's 8,200 new cases of childhood cancer each year.

But Amber — pictured in the book getting a CAT scan while clutching her teddy bear — should inspire action to topple those statistics.

Or so this mother hopes.

"My reason for persisting is to take the focus off the statistics and put it back on each individual person. Amber is a symbol of the millions out there," she said, tapping the cover photo on one her book prototypes.

Ideally, Ms. Stiewing would like to see all the cancer organizations work together to solve the international problem the disease has created. She downloads reams of information from the World Wide Web and considers the information highway to be a step in the

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right direction.

But between politics and confused studies, a cure is not coming fast enough. "I would love to save the world, but I can't," Ms. Stiewing mused. "I can help the world see as their own little girl. . . ."

After a child's death, many parents attempt to funnel some of their grief into a memorial project, said Janet Will, director of the pediatric hospice division at Johns Hopkins University Hospital in Baltimore.

"It brings some solace to their hearts," said Mrs. Will. One couple sponsored an (See AMBER, Page C2)

AMBER

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art contest to decorate the walls of the pediatric oncology unit. Their son, she recalled them saying, had "nothing to look at on all his trips there."

Sue Peterson of Glen Burnie served volunteering for the Hospice of the Chesapeake in the year following the death of her 16-year-old daughter, Mary.

"For me, her death was such a spiritual thing. It was hard to go back to work, back to the normal life," said Mrs. Peterson, a registered nurse who has been doing home visits to hospice families for four years. "Hospice is something that I know I will always do to some extent."

Ms. Stiewing has been similarly inspired by her experience. And she still wants to change the world. "We know what causes cancer. We know how to treat it. Now why can't we cure it?" she asked, frustrated by her question's rhetorical nature.

Over the years, she has researched cancer, updating contacts and mailing lists from Amber's treatment, when pediatric oncology was still in its infancy.

Newsletters, newspaper clippings and personal correspondence are all filed away in a box labeled "The Secret Legacy" that sits at the end of her bed.

Most of her research focuses on "alternative" therapies, which she believes families need to be apprised of when a cancer diagnosis is made. "Chemotherapy and radiation are not for everyone," she said.

She took Amber out of the country to the Bahamas to receive controversial immunotherapy and faced the wrath of the medical establishment upon her return.

"It's hard to make money off of apricot pits and herbs," she said, referring to the experimental drug Laetrile, which is still undergoing scrutiny by the FDA. "We spend \$100 billion a year on cancer. What are we doing with that knowledge? For me as one mother, it makes my task somewhat fruitless to face that. But it also makes this book all the

more important."

For the past 13 years, Mrs. Stiewing has earned a living varnishing boats. In 1988, she published a video on varnishing, which is now outdated, she says. This summer she plans to self-publish a varnishing manual, which she hopes will pay for the first print of Amber's story, "Embrace the Angel."

The book encompasses Mrs. Stiewing's troubled childhood in California, as well as Amber's in Connecticut. It traces their mother-daughter plight through poverty and sickness with sometimes brutal honesty.

This excerpt was taken from her daily journal three days before Amber died.

"The tumor is oozing all over. . . . She continues to beg me. 'Mom, please help me. . . . Mom, please. I'm begging you. I wish I had the guts to overdose her. It would be so easy, just load up the syringe with morphine and inject her. THE END. But how can I? I would be killing her. After all, I created this child. . . . I gave her life. How can I take it away?'"

Winter is the slow time in boat work, and Mrs. Stiewing has filled the gap taking care of her son, Toby, 13, doing re-writes and going through the volunteer program at the Hospice of the Chesapeake. She says each project brings her closer to fulfilling her promise to herself and Amber.

And even though she sometimes expects her daughter to come bursting through the door, boyfriend in tow, she said the most painful part of her grief is over.

"I am joyous that I had her for that time," Ms. Stiewing said. "I'm not sad that she's gone anymore."

Ms. Stiewing is still looking for members of the public to review copies of "Embrace the Angel." To receive a review copy, write to Ms. Stiewing at P.O. Box 63, Riva, MD 21140.