

"It's the end of June, and my little girl has pneumonia, again. This time the x-ray shows it might be pneumocystosis. I took her home, gave her medication, and called the doctor because she got worse. The doctor told me that my little girl does not

# One Family's Autumn

Autum Aquino, 6, and her family face AIDS.

Story And Photos By Kevin LeDuc

meet the guideline for him to put my baby into the hospital. This time I had a very hard time with her doctor. I got mad and upset. I

felt he didn't really care how I felt, or what I wanted.

You see, I know my baby is going to die. I don't know when, but I do know she will never see her teenage life. This is really what our life is about. We just sit and wait for her to take a turn for the worse. We pray she doesn't. We live one day at a time; we try to do as much as we can to show her the different things in life."

—*Diary of Theresa Dannemiller*

**F**ive years have passed since Theresa Dannemiller wrote in her diary about her sick daughter. In her struggle against AIDS, Autum Aquino—just six and one-half years old—has survived numerous pneumonias, infections, and three bouts with death.

It's late afternoon, 4:30 p.m. or so, as I head to meet the Dannemiller family, the unseasonably warm weather having moved out to sea. In the dark and bitter cold I walk across an empty lot. As I approach the side entrance

of the large apartment house, a voice echoes from the interior: "I came out to tell you something before you go inside," the voice says. Now the porch light casts a dark shadow over a thin, worn frame of a man. His eyes are set deep within a bony brow. As he speaks, light reflects from his broad cheek, throwing a contrasting shadow across an exhausted, ageing face. "I want you to take it easy with her. She had a treatment at the hospital today, and she is not doing well. She will talk, but she's very weak. So just be easy on

her, OK?" says Theresa's ex-husband Tim Dannemiller.

As we enter the kitchen, the sounds of little girls' voices as they play fill the air through the porch. A small table with a setting for three sits in the center of the room. In the far corner, a tattered pair of sneakers and a small load of laundry sit atop the washer/dryer awaiting the next wash. Leftover holiday pastries sit on the counter, and I sense the secure activity of a busy household.

Tim leads me into the living room.



**Above:** Autum wears her quilt. The background of the quilt is a lively pattern of her favorite Disney cartoon characters, Daisy Duck and Minnie Mouse. The oak tree that stands on the front of Autum's quilt will be decorated with leaves bearing messages from loved ones.



As we pass through the doorway, I step over a child's safety gate used to prevent Misty, Autum's four-month-old puppy, from messing on the living room carpet. I am greeted by Theresa, and she is noticeably weakened from her day's hospital treatment. Clothed in a long housecoat, she curls her petite body into the far end of the sofa—as she sits, the cushions of the couch envelope her.

"I feel I've been living in a dream, a terrible bad dream," she says in a quiet voice. She received a telephone call in 1986 bearing the news that her ex-husband, Jorge Aquino, and father of her daughter Autum was in a Manhattan hospital. Jorge Aquino was dying.

*"In November I found out Jorge was dying from AIDS. I called my doctor and was given the test for the antibody. My test came back positive. I couldn't believe it! There was only a one percent chance of having HIV."*

"Jorge was a strong man," she says as the hum of the air purifier emanates from behind the couch. Aquino served as an infantryman in the U.S. Army. During the Vietnam war Aquino and three of his buddies were blown up in a Land Rover. Aquino, the only survivor, suffered massive internal injuries and broken bones. In a full body cast for nearly a year, he was given morphine to help control his pain. He suffered from partial deafness and continuous flashbacks. Back home, Aquino began using heroin to suppress his pain. "You see, he didn't know what drugs could do to him. People ask me if I am angry at Jorge for giving me AIDS. I am not. He didn't know, but I am angry that he didn't tell me after he found out. I am angry that his shame kept him from telling me," Theresa says.

News of Jorge's death at 85 pounds and testing positive for the HIV virus was devastating enough for Theresa Dannemiller, but fate had yet another curve ball to throw her...

*"In February 1987 my little 20-month-old girl got sick. I took her to the hospital, we stayed one week. She was tested for the antibody and was found to be HIV positive. That was the start of our nightmares. My baby just got worse."*

Shrilling voices and pattering sounds of bare feet on the wood floor interrupt our conversation. "Quiet," Tim says as three dark-haired girls run into the living room. "When are we going to eat supper?" they cry. "In a while; be quiet; your mother is sick," Tim says.

Autum, the frailest and most petite of the three, bounces to her mother's side. "Can Stacia stay for dinner, Mommy, please, Mommy, please? Can she stay?"

"Go into the kitchen and play with Misty," Theresa responds. "We will see in a little while." I watch as the two sisters traipse with their friend back into the adjoining room.

I am struck with the normality. Screams and laughter transcend over our conversation. "I live for Autum. She was such a beautiful baby," Dannemiller says. Born March 3, 1985, Autum was two weeks overdue. She weighed in to the world at eight pounds even, and she was 21 inches long. "I almost miscarried her when I was four months pregnant. I was severely anemic and had to be given three pints of blood," Theresa says. Dannemiller continues on, remembering a chilling experience in the emergency room at Eastern Maine Medical Center in Bangor as if it were yesterday. It was a March evening. Theresa brought her baby to the emergency room with dehydration and a 104-degree temperature. Theresa explains that her ex-husband had recently died from AIDS and that she too had tested positive for HIV. The doctor turned away and walked out of the room. After some time nurses entered the room in 'moonsuits,' wrapped in gowns, masks, caps, and gloves. They took Autum and Theresa to a closed section of the hospital. In complete isolation they waited for hours as administrators hunted for a physician who was willing to care for Theresa's baby. "It was terrifying, and I felt abandoned," she says.

Nearly four years have passed since that evening, and the Dannemiller family continues to fight for their lives in their battle against AIDS. They have endured many illnesses and have survived numerous blows of bigotry. "I was tired of hiding in secrecy, of telling lies, of telling people my daughter had heart disease or anything else but

AIDS. I didn't want to tell Autum and I was afraid to go public," Theresa said.

Only through the persistence that a five-year-old child has was Theresa able to gain the strength to go public. At a doctor's office during a routine visit, Autum overheard her stepfather talking about sending her to a camp for children with AIDS. Later, while reading the book *In Absence of Angels*, by Elizabeth Glaser, Theresa followed a parallel story about a seven-year-old girl named Ariel who died from AIDS. While she lay in her bed crying, Theresa looked up to see that Autum had come to her side. Autum said, "That's what I have, isn't it, Mommy?"

As time passed, Autum began to insist that her friends at school know she has AIDS. But knowledge about the existing social stigma toward people with AIDS stopped Theresa from telling her secret. One afternoon, Autum came home from kindergarten with a story about her classmate Jason, who had told their class during show-and-tell that he had diabetes. "It's not fair, Mommy. Jason told about how he was sick and missed school, and about the special medicines he had to take. I'm just the same as he is, you know," Autum said to her mother. Theresa realized that Autum was right—she was not different.

*"With each new death I feel a loss of my own life. The pain of these unknown people is my pain, too. I cry as if they are part of my family, and really they are! The AIDS, death, sickness, and worry has taken its toll on me. There are times I just want to give up and hide, so that I don't have to deal with AIDS, but I can't. It's all around me. AIDS has become my life—I live to fight AIDS and teach people about AIDS. I pray that someday people will understand and help one another."*

The Dannemillers' past is filled with stories about prejudice and discrimination. There are stories about how Tim was fired from his job, called a "no-good homo" while he walked downtown, about how he was abducted from his car at a stop light in Portland and beaten, of how people shot out the windows of his West End house when they found out he had AIDS. Theresa tells of her frustration with the ignorance from medical



professionals, and how a physician once asked if baby Autum were a lesbian; of nurses who refused to draw blood from Autum.

*"The woman did not want to take blood, and as we were getting ready to leave, she turned around to one of her co-workers and told them not to let anyone sit in the seat until they were able to wash it."*

She has listened to people talk about her family, about how they don't want to be around her, of how her children don't belong in school, and about how the children in the old neighborhood played the "AIDS Game" on the playground. "Ja'nette, come here please," Tim calls out to Autum's sister. "Tell us about the AIDS Game."

"Well, a kid picks someone out and

says they have AIDS, then all the other kids run away from that person, or touch them, and fall to the ground and die," Ja'nette says. Just at that moment a high-pitched yell pierces through the laughs from the kitchen. "Misty, stop! Stop!" Stacia screams as she runs to the living room. "Misty is jumping on Autum and she won't stop," says Autum's friend.

"Autum, what have I told you about not letting the puppy jump up on you? She might scratch you," Theresa says as she motions for Tim to attend to Autum.

"Ja'nette, how did you feel when your mother went public about Autum?" I ask.

"At first I was afraid—I didn't want to because I was afraid that I would lose my friends, but after the story was in the newspaper, my friends at (Howard

C. Reiche Elementary) school told me they would never leave me, that they were behind me 100-percent," she said.

**R**unning into the room with a full head of steam comes Autum. "Mommy, Mommy," she tugs at Theresa's night robe. "Can we put up the Christmas tree tonight, please; can we please?" she asks. "Yes, yes! Let's put up the tree!" chimes in Ja'nette.

Tim says, "No, not now."

"Maybe for supper Dad is going to get a pizza. I don't feel up to cooking tonight," says Theresa. In unison the girls jump up, cheer, and run out of the room.

Picking up where Ja'nette left off, Theresa tells me that she's been quite happy with the way things have turned out in Portland, and particularly at the





Tim Dannemiller with Theresa in the living room.

award-winning Reiche School. "It could have gone the other way," she says. The school has distinguished itself with its progressive, informed approach to the challenge—both as educators and as a body of students—since day one and well before in the deftly handled and thoughtfully considered days leading up to Autum's attendance. Many other schools might not have been equal to the task. Moving to Portland, going public, with the media behind her, Dannemiller spends her days caring for Autum's and her own health, and she conducts AIDS education seminars at high schools throughout Maine. "I don't know how much longer I can do this. I am tired. The only reason I continue is because of the girls—if I didn't have the girls I would have given up by

now," she says.

On November 20, 1991, at an AIDS education seminar sponsored by Boise Cascade at Telstar High School in Rumford, Maine, the Dannemillers were confronted with social misapprehensions that were an embarrassment to Maine. After the seminar, Tim and Theresa fielded questions from the audience, which were sent to them on handwritten cards. A sampling: "I think all the AIDS victims should be shot like interbred cats;" "AIDS—Another Infected D---Sucker;" and "If you get AIDS from a blood transfusion, that's too bad, but the gays should die from it!" Theresa was asked, "How does it feel to be f---d, and then find out you have AIDS?;" "How does your daughter feel now, knowing that she is going to die?;" and "How many guys have you

done, and do any of them have AIDS?;"

Tim returns with dinner as Theresa calls the girls. The aroma of a hot double-cheese pizza fills the room. The girls clamour into the kitchen. Autum is jumping up and down and clinging to Ja'nette as the sisters head toward the table. Paper plates in hand, they grab hot slices. Tim takes his portion to eat in the living room where it is more quiet and he can watch the news. "Oh, no, look... Misty messed by the stove," shouts Stacia. A moment of hysteria follows with "yucks" and "ughs" ringing in the air. But the crisis is short lived. Tim cleans up the mess.

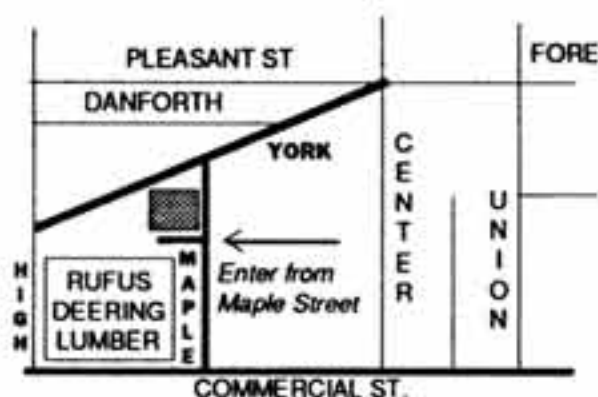
**E**xcited, the girls talk about what they want for Christmas. Ja'nette would like an electric keyboard and a Nintendo game. Autum wants a doll house, a little singing mermaid, and a pair of ice skates. I leave to watch the television with Tim as Theresa takes advantage of the few minutes to plan the remainder of the evening. She had planned to put the Christmas tree up on Friday, "But I do try to give Autum most of what she asks, because I don't know what will happen tomorrow." Theresa's game plan is to put up the tree now, "hook up" Autum to her feeding machine, and put the girls to bed by eight o'clock. Then she plans to relax and watch "The Judds' Final Concert." Theresa is not a country music fan, but she feels that Naomi Judd, who is suffering from Hepatitis II, is "courageous," and is an "inspiration" to her.

On the table sits Autum's report card. "May I read this?" I ask, picking up the envelope. Autum is a first grader at Reiche School in Portland and has just completed the opening quarter with her classmates. "Autum's teacher, Kristy Johnson, told me yesterday that Autum is an effervescent, bubbly child who likes fairy tales, especially Cinderella, and she also told me that Autum was given a special 'Peer Recognition' award," I tell Theresa, who smiles. Opening the report card, I read Mrs. Johnson's comments. "Autum works very hard at school. I would like to see less visiting during work time, though. Keep up the hard work!" 'Satisfactories' are marked in all areas, except for spelling and neatness in writing, where Autum needs some improvement.

"Autum missed just six days of school?" I ask. "Yes, she loves school,

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**Photo right:**

Autum, center, twirls with Stacia while Tim works with the tree.

and it's hard to keep her home. Autum has said to me that when she graduates from high school she will come out of school, and not until then. It's scary. Most people are afraid of contracting AIDS from us, but we, especially Autum, now that she is in school, have a greater chance of catching something that can kill her. You see, Autum's immune system is getting weaker, and she's becoming exposed to a lot more infections from children at school, and some she just can't fight against," Theresa says. "Last week," she continues, "Autum came down with red eye. We took her to the doctor, but they told us we would have to wait to see how it progressed before giving her any medication. Well, later that day, Autum's eyes became swollen shut, and a greenish puss oozed from them. I am angry. I'm tired of ignorant doctors and being treated like second class. My girl deserves better than that!"

*"Like countries fight wars, we are also fighting a war. We are not only fighting AIDS and death, we fight society and ignorance of people who feel that we have no rights. Sometimes I feel this is all a dream, and I am going to wake up and find our nightmare is over. I know it is true, and I have to deal with it. If I didn't have some very caring people to stand by me and help me, I don't know what I would do. I have to make life the best it can be for Autum when she is well and sometimes forget that she is going to die. When she gets sick it's like another slap in the face, and I remember what's going to happen to her."*

**S**ince September, when Autum began attending school, she has contracted a bacterial virus, influenza in her back lung, streptococcus, a type of blood bacteria, an ear infection; her asthma is acting up, and she has had two cases of pink eye. "It's been one continuous infection after another," Theresa says. To help Autum's immune system fight against impending infections, her doctor is going to start I.V. gam-







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maglobins very soon. In September, Autum's T-cell blood count was 2,400; now it is 573. When the T-cell count drops below 500, her physician will begin AZT treatment. T-cells are lymphocytes which, as defined, "produce a wide variety of mediators that are significant in many immunologic processes."

She is currently taking lanoxin (to regulate her heartbeat for regular blood flow); lasix (to get rid of excess body fluid); and zentolin and intal (two inhalers for asthma and to keep lung fluids moving). Pneumocystosis is an acute pulmonary disease which occurs in immunodeficient patients.

"Autum is dying, and I am getting sicker, too. Admitting this has been the most difficult thing," Theresa says. "People stop me on the street because they saw me on television—they wish me well and tell me how courageous and strong I am. I am not. "When Autum dies I am going to be hysterical. I don't care what happens to me afterwards, but I am going to see my baby through this."

Ja'nette walks into the room and sits on the couch next to her mother. "Mom," she says as she taps Theresa on the shoulder, "When are we going to put up the Christmas tree?"

"Soon," answers Theresa. "Tim needs to get it out of storage." Theresa tells me they have had a green scotch pine for eight years, and that it is ragged and old. They are unable to have a live tree because the tree's natural fragrance is toxic to Autum's fragile lungs.

**A**utum and Stacia jump over the child's gate and dance across the room, repetitively asking about the tree. Tim stands up. "OK, I'm going now." Excited, the girls jump up and down with joy. Ja'nette runs over, turns on the stereo, and instantaneously begins to sway her hips to the music. "Don't you dare, Ja'nette—don't even think about it! You know I don't like you imitating Madonna," Theresa says in a parental tone of voice. Autum and Stacia are rolling on the floor, tickling and laughing at each other, as Tim brings the tree. I settle into my place on the sofa and watch the project unfold before me and drink my Pepsi.

"Christmas is a happy and sad time. Mostly a sad time for us," Theresa says.



Gift giving is not a traditional priority in the Dannemiller household at Christmas. The gift of life and being together for another holiday is their treasure.

"A birthday for us is a very happy time. It means we have beaten AIDS again. It is also a very scary time for us," she says. Autum has already begun to tease for her seventh birthday party. She wants to have a Daisy Duck Party with family and friends at a Chuckie Cheese restaurant. "I can't plan it. It's too far away. Three months is like a lifetime," Theresa says. Ja'nette jumps into the conversation. "I don't think about the future, or worry about tomorrow, because it's always today." Ja'nette is the only member of the family who does not have H.I.V. The lessons she learns from her parents and Autum will carry with her into adulthood. Theresa knows that the road before Ja'nette will be a difficult one, and she has painstakingly made efforts to plan for her future. Ja'nette has been receiving counseling for the past four years in preparation for the deaths of her family. Theresa has stipulated in her will that Ja'nette can choose to live with either her natural father's parents or with Theresa's sister, Lynn Woods, and her husband.

The decisions that Theresa is forced to make for both of her daughters are not easy ones. Deciding who is to parent Ja'nette and how to bury Autum as well as herself at the age of 28 is unnatural.

"People think I'm this big strong person," Dannemiller says. "I've seen other women lose their children and I don't know how they survive. I pray I will be as strong as they were."

The stress of living with AIDS is so overwhelming that Theresa wonders how much further she can go. "When things become too hard I go to the bathroom. Everybody needs a screaming room. The bathroom is my screaming room. When the stress is too heavy and I lay awake at night, I turn the scalding hot water from the shower onto my body until I can't stand it...and I scream and scream," Theresa says.

"I told my father last week that I had made Autum's funeral arrangements. He asked me if I wasn't putting the cart before the horse. I told him that the horse is coming quickly."

*"I am also sick, and now I know I will*



*also die from this disease, but not yet—I can't die yet. I have to take care of Autum first. Dear God, please let me take care of my baby."*

Autum's body is getting tired, as are Tim's and Theresa's. Theresa is entering into "the wasting" process, a process that Tim has already endured for eight months. 'Wasting' is the painful course of chronic diarrhea, stomach cramps, vomiting, and indigestion that is accompanied with night sweats, chills, fever, and dramatic weight loss. Theresa has lost 35 pounds in the past year and now weighs in at 97 pounds. "We live with AIDS every day. We view death as something not to fear, it's a normal part of life," Theresa says.

"What scares me," Tim says, "is not death, but the process of dying. Facing family and friends and the tear-jerking goodbyes." Tim and Theresa have exchanged power of attorney and medical rights in their living wills, and they have carefully written and organized the process of their wake and funerals. After their death, Tim and

Theresa will both be cremated. Tim wants to have his ashes spread somewhere; he has yet to decide where. Theresa wants her ashes to be laid to rest alongside her baby girl.

Autum is forbidden to choose the process of her death because children cannot have a living will. The right to life laws prevent this choice in order for a child to be taken off life support, or given no medical treatment, it must be first determined by a physician that there is no hope for survival and that the child is ultimately suffering from a terminal illness. For Autum the process may be made easier because she is a "no code" and will not be resuscitated in the event of respiratory arrest.

Autum's funeral will be held at St. Luke's Episcopal Church in Portland. She will be cremated with her pillowcase and buried with her mother. Theresa says, "I believe strongly in what God says in the Bible, 'Ashes to ashes, dust to dust.' Autum does not belong to me... She is a gift, on loan. She belongs to God." □