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Kaitlyn's legacy

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erry, Brad and Kelly Langstaff are now a close knit family of three since the passing of Kaitlyn. Inset: Kaitlyn Langstaff in March 2002, prior to contracting Toxic Epidermal necrolysis, a severe form of Stevens Johnson Syndrome. Photo by R. Allen Schnoor

stricken nine-year-old
aves a community
mourn and
celebrate her life

By Julie Davis Berry

Executive Editor

Kaitlyn Langstaff, the nine-year-old girl stricken by a severe allergic reaction to common children's over-the-counter medication 20 months ago, died a week before Christmas, leaving her mom that she "wanted

to go to heaven." The spunky little girl whose struggle inspired a large outpouring of support from the community could be described by many adjectives: smart, funny, pretty, gracious, outgoing and most important, inspiring. She had been in and out of the

hospital this year due to the fact that her lungs were so damaged by her disease that they were deteriorating. Kaitlyn was stricken with toxic epidermal necrolysis, a severe form of Stevens Johnson Syndrome, 20 months ago while on a trip to central California with

her family. The disease attacks the skin and mucous membranes and causes lesions that resemble second-degree burns.

The family had hoped that Kaitlyn would beat the disease and eventually have cornea transplants and other operations to restore her vision and breathing. But this summer the disease quickly progressed. The Langstaffs are just happy for the time they did have with Kaitlyn.

"Most people who die of this disease usually die within the first few days due to respiratory failure," said Kaitlyn's mother Kerry.

"So, it was a miracle that she lived as long as she did. Towards the end it was very peaceful and she just kind of slowed down and then she died."

School had always been very important to Kaitlyn and she attended class a week before she

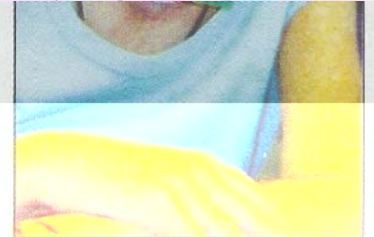
died at Forest Hill Elementary School. Her mother said that days before she died she was worried that she hadn't finished a book report.

Kaitlyn and her family were not the type to sit around and mope about the tragic turn of events.

The family arranged many fun outings for Kaitlyn, like a visit with the Dixie Chicks after a concert and a visit with Kristie Yamaguchi. And, right up until she died she was out and about experiencing life to the fullest.

"As sick as she was she had

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When Kaitlyn spent time in the hospital her parents brought her little dog Tessie to boost her spirits. The day after Kaitlyn died Tessie laid on the couch all day where Kaitlyn had always sat and wouldn't eat or bark. "We thought she was sick," said Brad. She's back to her bouncy self now after lots of attention from the family.

Kaitlyn

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some really good days this fall," said Kaitlyn's father Brad. "On Halloween she went to the Halloween party at Forest Hill and then she went out trick-or-treating at night. And, she went to *The Nutcracker* the Friday night before she died and then went out to dinner that night. But, in between she'd be very weak and have trouble breathing

and she was the one ventrally all the time."

The day before she died she looked at her mother and said, "I feel so loved." The next day Kaitlyn looked at Kerry and said, "Mommy I want to go now, I want to go to heaven."

The funeral was for family and close friends and almost 300 people came. On Jan. 17 there will be a memorial service that Kerry and Brad describe as a public celebration of her life.

"I plan to have live music, a

Stricken nine-year-old leaves a community to mourn and celebrate her life

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out at the hospitals in Southern California.”

“And, our neighbor Karon Pasos organized dinners,” added Brad. “The Girls’ Scout troop organized the food for the reception after the funeral. And the Indian Princess dads came over the day after Kaitlyn died and took down the wheelchair ramp and cleaned up the yard. It was just incredible how many people helped us out.”

The Langstoffs were tireless pioneers when it came to finding the right medical care for their daughter.

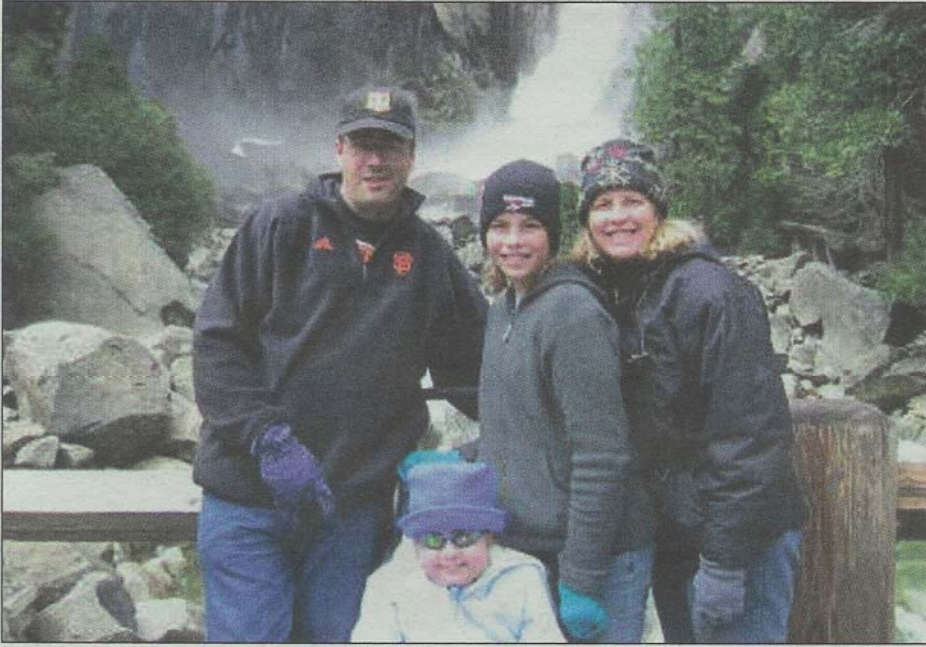
“There weren’t really a lot of people out there with the same problems like Kaitlyn,” said Kerry. “We had to carry backup ventilators in case her main one went out. They were just going to leave

her in the hospital and I ended up calling the director of the medical supply company and told him that it was up to him to get my daughter out of the hospital. And, he did. Now three other people across the U.S. are able to use it [portable ventilators] because of her. At least we’ve been helping other people with these experiences. We have a brother of a little boy in Texas who is in critical condition with Stevens-Johnson who contacts us and asks us questions.”

The couple has a lawsuit pending with the maker’s of Children’s Motrin which will be heard in federal court in San Jose in October.

But for now the family wants to focus on the good times with Kaitlyn.

Brad, who had been laid off a few months before Kaitlyn got sick, was



In April the family hiked to a waterfall in Yosemite with dad Brad pushing Kaitlyn's wheelchair up the steep hiking trails. Although it was satisfying to reach the waterfalls and let Kaitlyn feel the spray of water on her face and touch the cliff face the trip was not without its challenges. While driving, a battery caught fire in the van just a couple of feet from Kaitlyn's oxygen tank, and Brad quickly extinguished it.

Kaitlyn's primary caregiver. "As hard as it was taking care of Kaitlyn everyday, I loved taking care of her," said Brad, his voice breaking. "It was the best job I could ever have."

Kerry smiled as she remembered, "We asked all of her friends and family to write Kaitlyn a note and we put them into her casket. And in my note I wrote 'Kaitlyn make me a rainbow so I'll know you are okay.' And when we drove into the ceme-

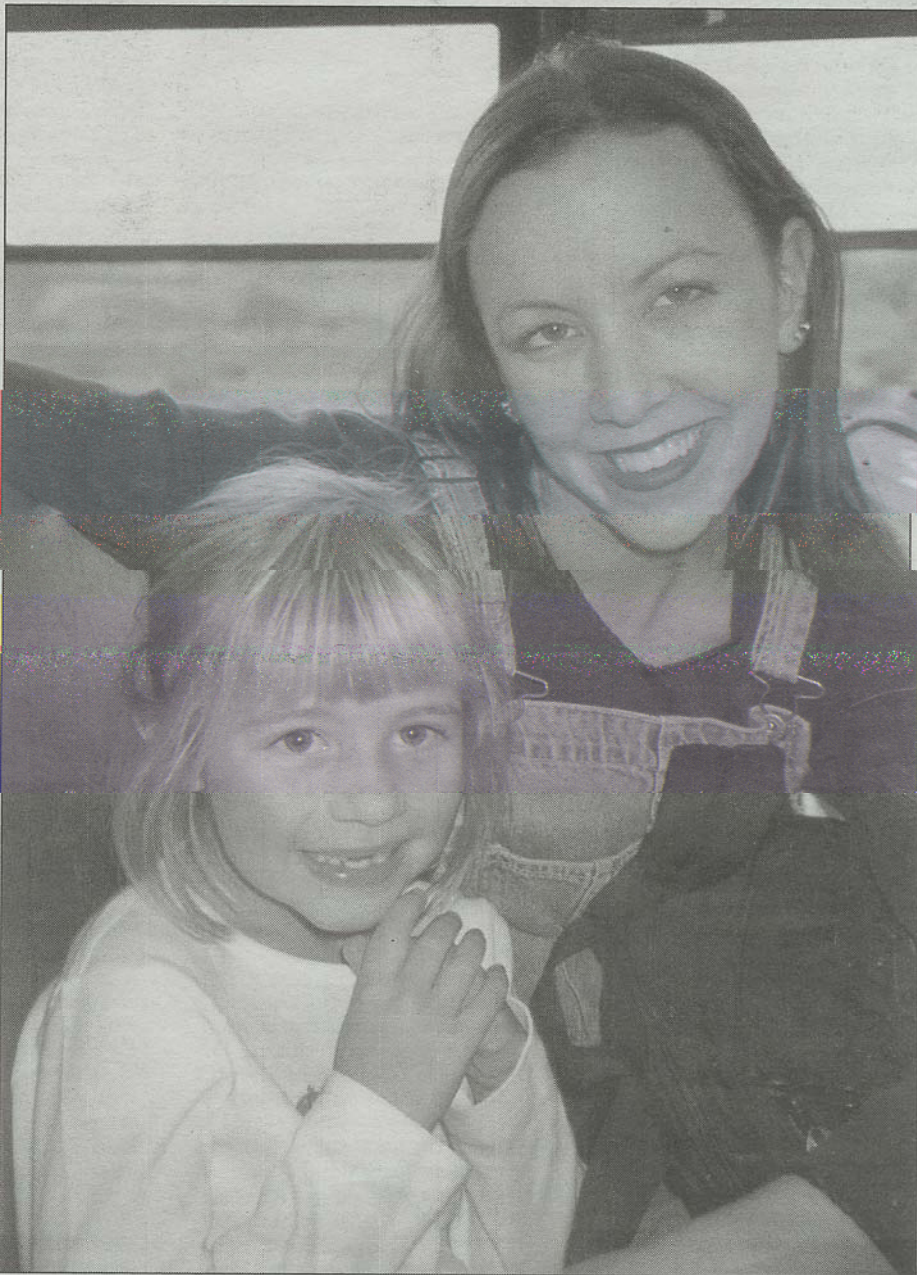
tery there was a huge rainbow that everyone saw and I knew that it was from Kaitlyn and that she is in a better place."

In lieu of flowers, the family asks that donations be made to the Silicon Valley Children's Hospital Foundation, PMB No. 280, 1600 Saratoga Ave., No. 403, San Jose, CA 95129. Put "In Memory of Kaitlyn" in the memo portion of the check. Cards may be sent to the Langstoffs at P.O. Box 3731, Saratoga, CA 95070.



A public memorial service will be held for Kaitlyn Langstaff on Saturday, Jan. 17 at 2 p.m. at Westgate Bible Church, 1735 Saratoga Ave., San Jose. This event will be a celebration of Kaitlyn's life. There will be music, a slide presentation, children's stories, special speakers and a brief "open microphone" session where people can share a special memory or story of Kaitlyn. Following the service there will be an outdoor balloon release where everyone is encouraged to 'send a message' to Kaitlyn.

For directions to the church and parking information visit www.westgatechurch.org/generalinfo.html or call (408) 252-3700.



Kaitlyn was in **Honora Lamotte's** Kindergarten class at Forest Hill. They were especially close. "She was an amazing little girl. She rocked my world," said Lamotte, who continued to visit Kaitlyn until the day she died. Here they are shown on a field trip.

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balloon release and maybe a butterfly release and a brief open microphone session," said Kerry. "We don't want it to be a sad thing."

Kaitlyn's older sister Kelly found a lot of solace spending time with her two best friends, Jacque Kuhny and Kristin Obermeyer. They were there the night Kaitlyn died along with "probably about 20 other family and friends."

Brad and Kerry are learning to get used to being a family of three instead of four. "I feel like we've been grieving the loss of Kaitlyn for the past 22 months so in some ways we were prepared. Inside she was the same, but she wasn't the same. We lost part of her a while ago," said Kerry.

"We were at the mall the other day and I saw the Limited Too store and I felt sad that I don't really have anyone to shop for there anymore. One of the hardest things to get used to is that we've been such a part of the Forest Hill and Rolling Hills communities for years and now next year we won't have anyone at either of those schools. We'll go to just having one child at high school."

Whatever their future holds the couple vows to 'have children in our lives.' In fact Kerry is going to continue being the Jr. Girl Scout leader of Kaitlyn's troop.

According to Kerry, all of Kaitlyn's friends have been very affected by her death. "I just took her friend Casey out to the cemetery last Saturday," said Kerry who gave each of Kaitlyn's friends her bracelets and stuffed animals to remember her by. "She wanted to see Kaitlyn's grave."

The day after she died, the couple boxed up all her medical equipment and donated it to the Flying Doctors. "We filled up two cars worth of stuff to donate," said Kerry. "We just didn't want to be reminded of that part. And, we wanted to give back to the community that had given us so much."

The family said they drew strength from the many community members who gathered around and reached out to help them while Kaitlyn was sick and lost when she died.

"There were so many people who helped us from the school communities to the Campbell Bobbysox community to the YMCA Indian Princesses," said Kerry. "There were a few people who really helped out a lot: Jackie Morris, who is the librarian at Forest Hill, let Kaitlyn become an assistant manager of her Bobbysox team and she became like a second mother to Kaitlyn. Her Kindergarten teacher Honora Lamotte came over to the house every Friday and brought her gifts and joked around with her. Tammy Davies and her family were a great support to us, even flying down to help

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"We are three of Kaitlyn's best friends, and we have known her for a long time. It would be very meaningful to us to tell so many people in the newspaper how great a daughter, sister and friend Kaitlyn was and still is. Kaitlyn will always be that hip, spunky, smilin', beautiful kind of a girl to us that she always was." – **Madison Vlay, Casey Morris, and Ariana Gomez**, fourth graders

"Jackie put a bracelet on Kaitlyn in the casket at the funeral home and we all have a matching bracelet." – **Ariana Gomez**

"As sad as it is, I realize that Kaitlyn is in a better place and she is looking down on us and smiling." – **Madison Vlay**

"When softball season started Kaitlyn asked me if she could get a uniform. She wanted to throw out the first pitch of the softball season, and after every practice she would practice pitching and try to aim. And, on opening day she got up out of her wheelchair and read a poem that she wrote the night before and then she threw out the first pitch and then she said, 'play ball!'" – **Casey Morris**



"The Langstaffs have been quite an extraordinary family, and right from the beginning they included the community in what was happening with Kaitlyn. So all of us became overwhelmed, not only by the situation but almost as if we were included as part of the family. And for the last year and a half we felt as if we were family. And that's part of the reason there was such an overwhelming response from the community. Also, individuals within Rolling Hills who were very skilled as far as organizing support systems, such as donations to the Langstaff family, reached out to help. Susan Harvel and Pat Thomas were very helpful with organizing things.

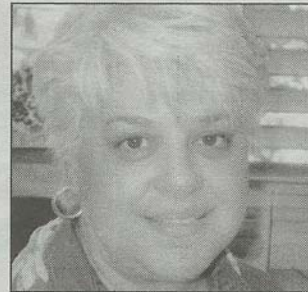
"The thing I really appreciated about the Langstaff family is that

them. Mrs. Wright took Kelly and her friends into the conference room and took care of them. Apparently that was what Kelly needed, was to be with her friends. My experience with adolescent children is that they react differently to adults when grieving. As I know losing a child is extraordinarily difficult but Kerry and Brad had so many ups and downs with Kaitlyn's illness and they knew that her body was...spent. The physical exhaustion must be incredible for the whole family. Apparently Kaitlyn had a tremendous amount of inner strength." – **Nancy Atkinson**, Rolling Hills Middle School principal



"Kaitlyn was a wild, smart little girl. Always very spirited. And,

even though I was always friends with Kerry and Brad and Kaitlyn, when Kerry called and said that she needed me it forged a bond and I became extremely close to Kaitlyn. I learned so much from her. You learn not to take life for granted. I think my life has changed from meeting her and being a part of her life, and I am just so fortunate that they let me become a big part of their lives. We miss her a lot but she'll always be a part of our lives." – **Jackie Morris**, Forest Hill librarian and family friend

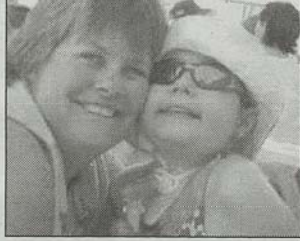


"I've always felt that the Langstaffs were a special family because they were so involved with Kelly and volunteering for Destination Imagination and their involvement with the plays. I knew they were a very caring, loving family and very supportive of their children. I really felt truly amazed at the outpouring from the community when Kaitlyn got sick. When people are in need people really will help out. When Kaitlyn died I was surprised to see Kelly come to school the next day but she needed to be with her friends. There wasn't a counselor at school that morning (due to budget cuts) so I was asked to help out with the students that wanted to go into a conference room to discuss their feelings about Kaitlyn. I asked them to draw pictures and express their feelings through poems and words, and I was really impressed with the how mature the kids were. A lot of the kids didn't know Kaitlyn directly but they were really touched by her illness and her death." – **Colleen Wright**, Rolling Hills school secretary



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"The thing I really appreciated about the Langstaff family is that they continued to be very involved with the school. Both this year and last year Kerry volunteered as one of the producers of the play. The other thing is the incredible strength that they showed when they came the day after Kaitlyn died because that was what Kelly wanted. I was so worried, and I felt so protective about them, because I've had a difficult personal tragedy myself, but they were amazing and it really helped some of the children to be able to go up and hug



"Kaitlyn was a wild, smart little girl. Always very spirited. And, she loved to read and she loved Britney Spears and wanted to be in the middle of everything going on. The girls were in Brownies together with Kerry as our leader, (and she is going to continue being the leader.) Kerry called me from down south when Kaitlyn got sick and wanted me to spread the word, and Madison and Ariana's mom and I flew down to L.A. and that made it real. You can hear things over the phone but [it's not until you really] see it you know how severe it is. But for some reason,

retary



"Kaitlyn was and remains a valued member of our fourth grade class. Her many friends welcomed and included her in our activities and happily created tactile projects for her to experience. On her good days she readily participated in class work and homework. Her love of learning, courage, and positive attitude inspired us all. She will be greatly missed, but her inspiration lives on in the hearts of her friends." – **Shirley Enos**, Kaitlyn's fourth grade teacher

“I live down the street and we’d play Barbies together. We went trick-or-treating together this Halloween. And, we liked to pretend we were Spice Girls. When she got sick, I wasn’t quite sure how she got sick but I missed her a lot. I visited her in the hospital in L.A. I called Kaitlyn before she died to tell her that I loved her.”

– **Alexandra Gulesserin**, fourth grader



Community News



"I've known Kaitlyn since preschool. When I heard she was sick I thought, 'oh great, why did this happen to her, she was one of my best friends.' I went to visit her once every month. I was sad when she died. The favorite thing I remembered about Kaitlyn was how she would always smile and how she would always answer questions really fast in class. — Kyle Gustlin, fourth grader



"I went into teaching to make a difference in children's lives and I've really found that they make a difference in mine. Kaitlyn's an example of someone who...she rocked me, she moved me in so many ways. She's definitely my sunshine girl. I picture her being five and her whole life ahead of her with so much potential. She had such a strong inner drive even after she got sick. Her time was short on this planet, but she affected us in such a short amount of time, it's just amazing. I learned, not just as a teacher, but as a human being you have these precious little spirits in here and it really is more about their spirits and not just about academics. And, her family is wonderful. I learned from watching the parents deal with all of this, they really appreciated everything even the car ride to school. I see parents just rushing to drop their children off and they are rushing through life and I think our society is just so fast-paced and even a microwave takes too long. I think Kaitlyn showed an entire community about what's important, about human connections. I'm so inspired by her and her affect on our world. She lived a short life, but she lived a good life, and she was loved and she loved us and she left us with that. She lives in our hearts forever. Whenever I get upset, I just smile because I know her work is done here and she's in a better place. I'm comforted by that. My community in particular, this school has been tremendous

each other in the world. I came over to the Langstoffs on Friday nights and Kaitlyn and I would tease each other and talk about cute boys. We had a great time. I love that kid. I always will. I'm lucky to have known her and to have had her in my life." — Honora Lamotte, Kaitlyn's kindergarten teacher



"I have probably learned more from Kaitlyn Langstaff and her family about setting priorities in life than from anyone else I've ever known. Kaitlyn's determination and grit constantly amazed me as she navigated through new life waters caused by her illness. I think Kaitlyn's stubbornness was key — she had a good head on her shoulders, and when she had that mind made up — look out! By sheer will alone, both Kaitlyn and her family did everything possible to keep their lives 'normal.' By watching their example, I've learned to slow down, take the time to appreciate the everyday things in my life. I hug my family a little tighter. I let little stresses go. I try to enjoy each moment given to me. Thank you, Kaitlyn, for teaching me these things." — Julie Dorsch, Kaitlyn's third grade teacher



"Kaitlyn was a beautiful, brilliant, talented little girl who was also quite stubborn. Her beautiful eyes sparkled when she smiled. I never saw her eyes again after she became sick. My heart ached for Kerry and Brad to think that they would never see her sparkling eyes, hear her laughter or her voice, watch her run, climb or swim again. Kaitlyn was the only second grader that I've ever known who would write To-Do lists and put them on her refrigerator. She was destined for wonderful things until she was hit by a tragic twist of fate. I told Brad and Kerry that Kaitlyn was like the little pebble dropped in the pond. Seemingly insignificant in the grand scheme of things, but her ripples have touched an endless amount of people and

Brad and Kerry and the seemingly endless amount of strength and determination they've been able to muster during this trying ordeal. They have earned many wonderful friends through the years by selflessly giving to their community—Brownie leader, play producer, Indian Princess Chief, school site council, leader of the Destination Imagination team—just the sort of people who put their kids and communities first. They were rewarded by an outpouring of prayers, love and offers to help from people in their community and beyond. They did everything humanly possible to help Kaitlyn while, at the same time, trying not to neglect Kelly as she entered her teenage years. I never once heard them complain about the hand they'd been dealt. With dignity and grace they continued to move forward and make the best life possible for both their girls. Kelly has also had a lot of support from other moms, dads, family and very good friends. This whole experience epitomizes what's really important in a child's life - moms, dads, friends and community." — Tammy Davies, family friend



"Kaitlyn was an inspiration to all of us. Her strength and love for learning taught us all to appreciate life. Through her difficult times, she wanted to come to school to continue her quest for knowledge. Kaitlyn's challenge brought our school community closer together. She will be missed but always remembered. The Langstaff family has contributed many hours in providing opportunities for our children. We look forward to them continuing to be important and valued school community members". — Scott Johnson, Forest Hill Elementary School principal



"Kaitlyn will always be the bright, beautiful, athletic "golden girl" of our memories. Her names and stories entertained

rushing through life and I think our society is just so fast-paced and even a microwave takes too long. I think Kaitlyn showed an entire community about what's important, about human connections. I'm so inspired by her and her affect on our world. She lived a short life, but she lived a good life, and she was loved and she loved us and she left us with that. She lives in our hearts forever. Whenever I get upset, I just smile because I know her work is done here and she's in a better place. I'm comforted by that. My community in particular, this school has been tremendous, the parents and the children and staff we just all came together. It's sad [that] it takes something so dramatic and horrible to make us remember what's important in life. But I think that that was her job here, it was to remind us of our connection to each other and our hearts and our spirits and how we treat

again after she became sick. My heart ached for Kerry and Brad to think that they would never see her sparkling eyes, hear her laughter or her voice, watch her run, climb or swim again. Kaitlyn was the only second grader that I've ever known who would write To-Do lists and put them on her refrigerator. She was destined for wonderful things until she was hit by a tragic twist of fate. I told Brad and Kerry that Kaitlyn was like the little pebble dropped in the pond. Seemingly insignificant in the grand scheme of things, but her ripples have touched an endless amount of people and have changed us all in positive ways. When you look at the Langstaff's who are starting their lives over as a family of three rather than four, the minor inconveniences or the little complaints of everyday life are meaningless.

"I have such admiration for

principal



"Kaitlyn will always be the bright, beautiful, athletic 'golden girl' of our memories. Her poems and stories entertained and inspired us. From hiking up a steep trail on a field trip to running relay races her spirit and enthusiasm was infectious. I am a better person for having known Kaitlyn and her wonderful supportive family." – **Carol Curry**, Kaitlyn's second grade teacher