

Norma's Remarks at Lori's Memorial Service

Finding the Good....

Those of us who were privileged to share Lori's life know her for her kindness and compassion. Lori wasn't a "material person"; she never wanted much for herself...a few Peeps, maybe some Gummy Bears... Her thoughts were nearly always about what she might do to make someone else's life a bit happier. Many of you benefited from some of her small but meaningful kindnesses.

I tried to think back to what fostered that simple but profound attribute in Lori's character. Lori wasn't diagnosed with CF until she was nearly 5 years old. She was fully aware that her life was changing, that the change was significant and that taking a lot of medicines and doing percussive therapy twice a day was not a normal part of a kid's life.

I told Lori shortly after she was diagnosed what all the "fuss" was about, told her about the disease and life expectancies. She was really too young to understand but I told her I would always tell her the truth, she could ask questions and I would always let her participate in any medical decision she was old enough to understand. To this day I am convinced that was the right thing to do. Lori was always able to discuss her health with friends, not be "too" hurt by rude or unkind comments about all the pills she took or the way she coughed. I believe this is what led to her unequalled medical compliance and compassion for others.

After our family adjusted as much as possible to our "new normal", it was time for Lori to rejoin her friends at nursery school. As we pulled up to the curb, the mother of one of the kids expressed her sympathies and then offered me her books on death and dying. Death and dying? I politely declined her offer and said if she had any books on Life and Living I'd be glad to read them.

That single statement changed the way we would approach living with cystic fibrosis...we would have hope, Lori would participate fully in life, setting life-long goals as any normal healthy person would, and we would do everything in our power to educate the public and raise desperately needed money for research.

As Bill and I think back over the years, we try to focus on the tremendously positive way in which Lori led her life.

The more we talked about Lori the more we realized how she was able to take nearly any adversity and find something positive in it. It's an old cliché but Lori really did make lemonade out of lemons!

The first adjustment after being diagnosed with CF was the routine of doing therapy...during the inhalation part we played games, we watched Sesame Street and during the pounding part we sang, figured out how many times we could sing Row Row Row Your Boat or Happy Birthday in 1 minute. When friends were there I offered to “give them Love Pats” so they would feel included and understand this was so important in Lori’s life...not something to be frightened of. When we were teaching Lori to breathe out, a sort of hissing sound, during vibrations, she dubbed them “Sammies” after Sammy the Snake on Sesame Street. We nicknamed the awful, noisy Maxi Mist Compressor “Max”, creating a new friend.

It was during Lori’s grade school years that she really shocked us all. At one of her Stanford appointments, Lori told her doctor she had a list of 10 good things about having CF. He was stunned and asked her what those things might be...she told him that number one on this list was the nice people she was getting to know and he was at the top of that list!

Lori’s compassion for other people was shown in many ways during her life. I recall that she and her best friend, Tara, decided to make every effort to be a friend to a boy in their class who was always in trouble. They thought if he had friends, someone to sit with on the bus and eat lunch with, he might not get in trouble so much! It didn’t work but, hey, they tried!

Lori grew up going to pretty much an all white grade school. Lori always befriended the new kid in school, the kids of other ethnic groups, the new kids from other countries who maybe didn’t speak good English or know our customs. She always accepted the differences in others and grew from these experiences.

During Lori’s school years she participated fully in school activities. In high school, she swam butterfly for the swim team, was a member of the National Honor Society, listed in Who’s Who in American High Schools, and was a member of the high school German club.

I had always told Lori that whatever she’d wanted to do, we’d find a way! That offer was really tested when, in high school, a 4 week exchange program was started with a gymnasium in Wurzburg, Germany. Lori was eager for us to host a German student. The dilemma was, if she went to Wurzburg, who would do her therapy? Not a problem. The student we hosted was delightful, wanted to learn how to do Lori’s therapy and talked with her mom about having Lori stay with them for the 4 week exchange. During a class trip to Berlin and East Berlin, even Lori’s high school German teacher and the teacher from the gymnasium in Wurzburg got involved in doing therapy. Lori participated in the exchange program twice, made wonderful friendships, and then went by herself to visit her new friends right after graduating from high school.

There were also times in Lori's life that were difficult. I recall that when she was starting her junior year she was concerned that she wouldn't have someone to eat lunch with. Her little "clique" had decided to leave her out! I told her that we lived in a community where new kids were coming in every year...a military community. I was sure that there would be new kids who needed friends...told her to just look around and find someone who seemed alone. Eyes rolling? You bet...but when she got home that night she had a whole new perspective on how smart her mom was! She found a friend who became her best friend for the rest of her life!

Lori had a passion for learning. She graduated 12th in a high school class of nearly 300 receiving 5 scholarships and several other awards. She loved to travel but travel for her wasn't just about going to a place; it was also to learn as much as she could about it before and while she was there.

Lori began her college years in Santa Barbara. She became very ill toward the end of the first quarter of her sophomore year. She faced a big decision...whether she should go back to Santa Barbara after Christmas vacation or stay home, attend our community college, and really get her health back in order. She called me during her final exams and said she had made a for/against list...reasons for returning to UCSB and reasons for coming back home to live and go to school at Monterey Peninsula College. Coming home had won, hands down! She approached this dilemma in life not with a feeling of defeat but of triumph. Even with all the health issues and hospitalizations, Lori completed her college education receiving her Bachelor's Degree in Psychology from Santa Clara University.

Lori had done some lifeguarding at a Y Camp and had taught swimming and done lifeguarding for the Santa Clara Y while she was in college. After graduation in 1994, she worked full time (a 30-hour week) at the San Mateo Y, with a couple of lapses in employment for health reasons, until the Friday before her final hospital stay.

Lori adored little kids and, knowing she likely would never have her own, she "adopted the children of friends and family" becoming a second mom.

During the intermittent times when Lori didn't have regular employment, she spent no time feeling sorry for herself. During one of those times she created a flyer which she distributed on doorsteps in more affluent neighborhoods. As a result, Lori had several regular families whose kids she looked after. She ended up doing child care for twin baby girls who, it turned out, were the granddaughters of Henry Fonda.

During another "in between day jobs" period Lori found another way to fill her time. Lori loved Beanie Babies and spent hours on the computer, during the Beanie Baby craze, trading them with other people who were hooked on the cute little creatures. This not only filled a lot of her day but also kept her connected with other people.

Lori had a lot of friends but only a couple of guys who were really special to her after high school. Even when those relationships didn't work out it was very important to Lori that she find a way to keep them in her life as good friends. There was never any ill will expressed toward anyone who passed through Lori's life!

I was always amazed by how positive Lori was during her many and sometimes very long hospital stays. One time when she had a room with a very sun-filled window, she grew tomato plants and gave them away to staff members. Lori always reached out to younger CF patients to try and make their inpatient experience more positive...I recall one girl perhaps 8 years younger than Lori, who had never been to Disneyland. She said her family didn't have the money to go. So, they set out to make that money,..Lori and her CF friend made Fimo jewelry and decorated picture frames with cute Fimo creations...to earn the money so Jenai could go to Disneyland. Other times they decorated the window of their room for the amusement of people going by and decorated their medical equipment with "happy" stickers!

Lori loved to play games and cards and many inpatient hours were spent playing rummy with her Dad and I. During the time when cross-infection wasn't yet an issue in the CF community, we would gather some of the inpatients in the family room and play rousing games of UNO. A good, hearty laugh was nearly as good as a percussion treatment!

As Lori moved into to what is considered the "older CF years" there was considerably more to face in dealing with CF. Each time a new challenge came up she accepted it and moved on. We talked sometimes about these things....She simply said, "Other people have had to deal with the and if they could, I can too"!

During Lori's later years she simply didn't have the time nor energy to enjoy socializing in a public way. The computer became her social outlet, primarily Facebook, because her connection with people who had been or were still a part of her life. She found friends from grade school, high school, nurses, respiratory therapists...people who were or had been an important part of her life. She was interested, not in just telling them about her life, but about what was happening in their lives as well. Their kids became the kids she wouldn't have!

Lori had so many hopes and dreams for her future. She wrote in her journal about how wonderful it would be after a lung transplant to not "think about breathing", to be able to climb mountains. She did believe that there would be a future. In her file is a brochure on "How to Adopt a Child". Sadly, Lori was not offered the opportunity for a transplant and that future she so hoped for.

Lori was a collector of memories, not material things. We are profoundly touched by all the messages people have left on her Facebook page. It is comforting to know that so many people were touched by Lori's life...she has left a tremendous legacy!

I am so proud to have had Lori as a daughter, to have shared our home with her for the past 6 years growing ever closer, and to have had her so lovingly call me "Mom".

I will miss her "I love you, Mom's". I'll miss hearing her say "I need a hug" and her cheery "Hi Mom" when she'd get home from work. But, mostly I will miss the essence of the wonderful young woman I was privileged to call "My Daughter"!