



Mary Beth Bresolin died in her sleep the morning of December 23, 2016. I've brought together articles included in the last four Living/Dying Project newsletters telling of Mary Beth's journey. She was a light to so many of her friends and family members. It was an honor to share this journey with her. We met in March, 2013. — Curtis Grindahl

Wrestling with Mortality

Mary Beth is a curious person. The discovery after many years of medical uncertainty that she does in fact suffer from a variant of ALS hardly answered her questions. In fact, it became the occasion for even deeper exploration. This was not how she imagined her life would unfold as she cared for her young son Nico while producing films from her home base in Los Angeles as a visual anthropologist. She'd traveled the world, always exploring, always asking questions. Hers has been a wonderful life of adventure, a life filled with friends and creative opportunities. But now she confronts a fundamental question about life. What is she to make of this latest chapter? What does coming to terms with this debilitating disease mean for her?

The phrase "wrestling with mortality" came very early in my conversation with Mary Beth. She'd known of the Living/Dying Project for some time and contacted us over a year ago when it remained unclear what exactly was contributing to her unrelenting physical

challenges. The journey had begun some years before with a fall on the trail when her ankle sud-



denly gave out on her. Although the symptoms manifested would later be recognized as suggestive of ALS, the first doctor who treated Mary Beth did not consider that possibility in her differential diagnosis.

Searching for the elusive cause of her difficulties Mary Beth endured two surgeries on her spine as well as a bone marrow transplant, but neither the pain she experienced nor the weakness that seemed to envelope her body were relieved.

Eventually, her fatigue made it impossible for her to continue the life she'd tried to maintain in Los An-

geles and she moved with her son to the home of a dear friend she'd known since the first grade. It was

in that home where I met her in my role as Client Services Coordinator for the Project.

Earlier this year Mary Beth began working with a new doctor who confirmed the diagnosis of a rare variant of ALS that involves growing debility of her lower extremities but allows her to continue to speak. At the time the doctor suggested Mary Beth might have only

months to live but later tests of her lung capacity indicated this journey will be a longer one, perhaps as much as a year or more.

I brought to our meeting the two year journey I'd shared with a man named Denlow who also confronted ALS. I understand just enough of this territory that I can listen with an attentive ear and offer support in the face of this unrelenting disease. Of course, Mary Beth is immersed in her own journey, measuring her capacity and willingness to meet the challenges that lie ahead. What she learns about others who've confronted this dis-

ease will not answer all the questions she encounters.

The one given is her love for her son who sleeps in the same room where her hospital bed sits. Artifacts of childhood are scattered around the room and mounted on the walls. This is at once a boy's bedroom and a sanctuary in which the deepest questions about living and dying are examined.

When I suggested to Mary Beth that I'd be interested in writing about her journey, the part of her that has for so long been committed to the creative process was intrigued and we had a conversation about how we might collaborate to tell a story that would both speak to readers of our newsletter and offer some insights that might prove useful for her son. She brought out her digital recorder and we began, despite her natural reticence about being the focus of attention herself. She is more comfortable asking questions than answering them and much prefers being behind the camera instead of in the limelight.

In these early months of getting to know one another it has become clear that first and foremost on Mary Beth's mind is how her illness and death will impact her son. It saddens her that she will not be present in his life to offer guidance as he grows up. The question is how best to prepare him for what lies ahead as well as how best to provide for him when she is no longer able to care for him in person. But she is also concerned how the physical deterioration associated with this disease will affect Nico. There are no easy answers here.

It was many months into our work when Nico asked his mother forthright questions about her illness and her death. The conversation was very matter of fact. Nico was comforted when Mary Beth responded to his question about where she would be buried. She offered the possibility she might be buried in nearby Olema. Some months before she and I had visited a small cemetery on Highway 1, nestled against adjacent hills. She appreciated the informality of the place, the simplicity.

As Mary Beth approaches the time when she will need additional care, her questions made me think of Denlow's wife Melissa who handled the logistics of his care. I asked Mary Beth whether she would wish to talk with Melissa and when she said yes, I contacted her. Melissa agreed. That will surely be a fruitful and possibly emotion laden conversation. In the meantime the reality of where this journey inexorably leads is present both in the hospital bed and the powered wheelchair that now sits in the garage. Soon that chair will be necessary to offer the physical support her weakening body needs. Yet understanding where the journey leads makes no easier the fact of coming to terms with its reality. The wrestling continues.

— Curtis Grindahl
Client Services Coordinator

*It's dark because you are trying
too hard.
Lightly child, lightly.
Learn to do everything lightly.
Even though you're feeling deeply,
lightly
let things happen, and
lightly
cope with them on tiptoes
and with no luggage,
completely
unencumbered.*

Aldous Huxley



Orphan

When we think of the word orphan the image of a child without parents comes to mind. As we get older it is likely that we'll experience orphanhood ourselves, the disequilibrium of living without our parents to anchor us to a shared past. Having lived without a parental anchor for many years, I now face the challenge of a different kind of orphanhood, one with even more disequilibrium.

I'm 50 years old and find myself with an orphan disease. These diseases affect so few individuals that there is little incentive for the pharmaceutical industry to pursue research or develop treatment. A disease qualifies as an orphan in the United States if it affects fewer than 200,000 individuals. There are more than 6,000 diseases that meet that criteria; diseases ranging from rare cancers to poorly understood viruses. There are millions of people in the world in my predicament. Many of these diseases severely impact quality of life while others simply terminate life, some quickly, some slowly. Unfortunately, I have a terminating orphan disease, a disease known as "the beast".

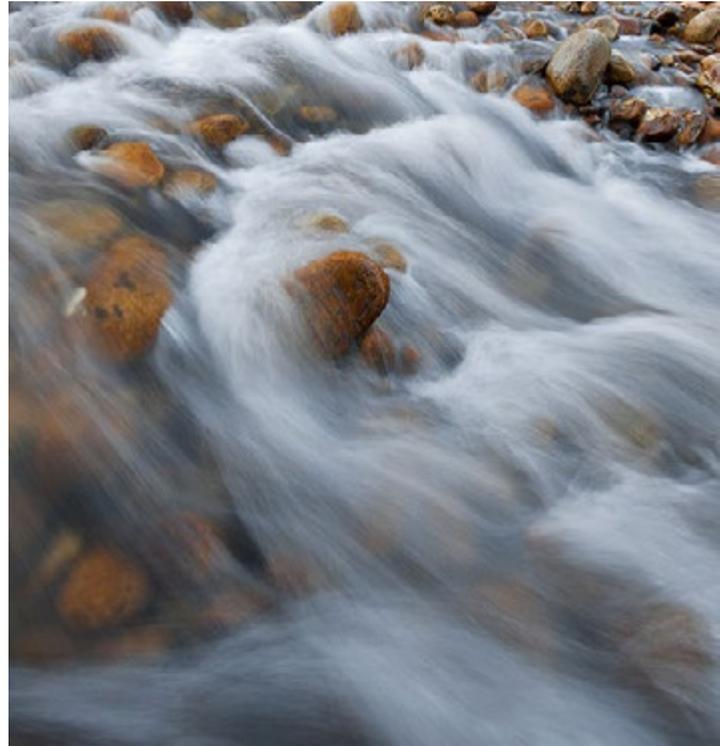
My search for a diagnosis has been a four-year battle, intensified by my need to find any disease as a preferable alternative to the one proposed by the fourth doctor I saw... ALS. Random, no known cause, no treatments, always fatal. Give me a tumor that can be seen. Give me a blood disorder that can be measured. Give me something to fight, but please don't give me this.

I was told by a doctor I met once for 30-minutes that I would die within 12-18 months. I was alone in his office when he gave me this news. Literally one minute we were discussing ice cream shops our kids like, the next he said, "Get your affairs in order right away." He shook my hand and told me he was sorry. To this day I am stunned that a person who works with illness, a doctor, could be so cold.

I rushed from his office to a toy store to buy a train set for my son, whom I then picked up from preschool. We returned to our home where I proceeded to enter a rabbit's hole of darkness. I remember lying in bed with my beautiful child in despair so deep I could neither speak nor cry. It was the day after my birthday, a week before Christmas, 2008.

Now, as my abilities diminish I continue to face the beast that will ultimately orphan my child. I struggle to understand and accept death so that my child can gain whatever is positive from this bleak prognosis. I do have the gift of a slow death and a clear mind. These are qualities described as the "curse" of ALS, but I am learning that they can be an opportunity. I stand at a portal of existential clarity: life, death, love, loss, past, future. I move in and out of this portal dozens of times in a day. I feel profound happiness juxtaposed with terrifying physical limitations and fear. My greatest challenge is to continue living fully as my body dies gradually, a complex lesson in practice to leave my motherless child.

—Mary Beth



It may be that when we no longer know which way to go we have come to our real journey. The mind that is not baffled is not employed. The impeded stream is the one that sings.

Wendell Berry

Still Worth It

When I asked Mary Beth whether she felt there is anything she wishes to say in the forthcoming Living/Dying Project newsletter we found ourselves immersed in a conversation about the reality of her physical challenges, measuring them against her desire to remain with her son for so long as she can. The title of this brief article came to mind. It really says everything that is essential for Mary Beth.

Yes, it is true, her body continues to succumb to this unrelenting disease, ALS. It is increasingly difficult for her to lift her arms and to use her hands. She now requires assistance to get out of the hospital bed that has been moved to an alcove off the livingroom of her friend's home.

When not in bed she is in a powered wheelchair. Granted that chair enables her not only to maneuver through the

house but also to wander down the street to the nearby park. With the converted van it is also possible for friends to drive her to



doctors' appointments and even to a housewarming she attended shortly before our conversation.

But her limitations also mean she is unable to volunteer at Nico's school. Beyond the fact she is no longer able to offer meaningful assistance to either students or the teacher, is the feeling that her appearance in the wheelchair is

an unsettling presence. As Mary Beth puts it, she has no wish to become the poster child for ALS. She is willing to share her experience with the folks who are concerned with end of life matters who receive the Living/Dying Project newsletter, but prefers not to answer endless questions from folks so clearly frightened by her reality.

Nico is slowly coming to terms with his mother's illness, but, understandably, he still wishes she could be the mother she once was.

Clearly, it is still worth holding on to this life that allows Mary Beth to remain a presence in her son's life, even if it is a diminished presence. Yet embracing what is left of her life leaves her open to the profound challenges that come with the disease that holds her in its grip.

— Curtis Grindahl
Client Services Coordinator

Hope is not optimism, which expects things to turn out well, but something rooted in the conviction that there is good worth working for.

Seamus Heaney



Life is Always Worth Living!



Rolling with Nico... the Festival of St. John at a village in France

I was surprised when I visited Mary Beth in February and she asked with a timid smile whether she was crazy to consider taking a trip to Italy with her son Nico who had been creating a family tree and exploring his Italian heritage. She was bound to her wheelchair by that time and required help getting in and out of bed. Although she could still move her hands and arms she lacked the control and strength to do much with them. Having a sip of water necessitated leaning over so she could reach the straw.

We often talk in these pages of the reality that facing a life-ending illness in no way obliges one to give up one's zest for life. We are the *Living/Dying Project*, after all. Yes, life with serious illness often carries with it significant limitations. The question eternally being asked is the one Mary Beth has answered over and over again in the affirmative. It really is possible to embrace one's aliveness, to choose life over and over again.

Mary Beth has attracted a circle of friends who've known her only since her diagnosis of ALS and only sitting in a wheel chair. While some of her family and friends were daunted by the challenges she faces, this group of friends finds nothing about her limitations an impediment to enjoying the moment. They often load into her van

with its lift to handle the wheelchair and head out for an evening of adventure. Mary Beth and her good friend Kathleen purchased memberships to the DeYoung Museum so they could view exhibits as well as enjoy *Friday Nights at the DeYoung* with music, dancing and a cocktail or two.

One member of this group, Joaquin, invited the gang to his home for dinner he prepared. Since the stairs make it impossible to get Mary Beth's wheelchair into his home, he cleared space in the garage and decorated it for the occasion. The pleasure they take in one another's company is real, as is the love and care they all provide for Mary Beth.

With this experience in the back of my mind and Mary Beth's question about a trip to Europe before me, it was easy to believe whatever challenges might lie ahead of her would be met with the resilience exhibited many times and with support from friends who would share the journey with her. And so the planning began.

Imagine the logistics... arranging a transcontinental flight that will accommodate a wheelchair as well as a van at the end with a lift to handle the wheelchair with Mary Beth seated in it the whole time. Imagine checking the width of every doorframe that must be passed. It was here that the home offered in Florence fell to the side. The wheelchair wouldn't fit. And the home of Gloria, her friend in Spain who planned to join the entourage, is on the third floor and the elevator hadn't been working for months.

Piece by piece each problem was solved... the elevator repaired the day before Mary Beth arrived! The trip that was planned for Italy instead became a trip to Spain and France... where they encountered the *Festival of St. John* in a small mountain village above the Mediterranean beach they drove to each day. The photo of Mary Beth and Nico entering the courtyard during the festival is above. It was taken by her friend Travis who came on the trip to lend a much-needed helping hand. What delight!

Mary Beth said during our conversations that if

she were to die along the way, it wouldn't be a terrible thing, though she knew it would be difficult for Nico. But it will always be difficult for him and this trip offered them a wonderful opportunity to share an adventure. Before her illness she envisioned exactly this kind of life for her and Nico. ALS may impose its consequences for the future, but it didn't stop this trip from happening.

I've been meeting with Mary Beth for two and a half years. She is a remarkable woman undaunted by what lies before her. She is inspiring in the simplest way. Next we prepare a ceremony for two of her friends who have offered to serve as Nico's god-mothers after Mary Beth is gone. She envisions a deck overlooking Tomales Bay with close friends present for the event. I promised to take a few photos after I officiate at the ceremony.

Apart from that we realize it is all beyond our control. But for today we embrace our aliveness.

— Curtis Grindahl
Client Services Coordinator

*Keep some room
in your heart
for the unimaginable.*

Mary Oliver

How Do You Say Goodbye To Your Twelve Year-Old Son?

My conversations with Mary Beth of late have focused on whether it is time to invite hospice into her journey. I've written about Mary Beth over the last three years I've been visiting her each week. She has ALS and is approaching the end of her travail. Her lung capacity has dropped below 25% which contributes to her diminishing ability to not only breathe but to talk.



Nico strolls with his mother.

When we met Wednesday at our regular time, in the shelter of large trees that offer a bit of shade on a warm morning, she suggested it is time to contact hospice. But before doing so she wants to discuss this decision with her twelve year-old son Nico. Mary Beth knows he has feelings about her illness as well as her pending death, but it is difficult for him to speak about them with her. She hopes a conversation about hospice will give him a chance to express his concerns, his fears. I offered to join them for that conversation.

Two days later, Mary Beth called and asked if I were available to talk with Nico. I told her I'd be there in twenty minutes. I found her in her wheelchair in her bedroom with her much loved neighbor Luisa who happens to be a nurse. Mary Beth had had a difficult day with much labored breathing. She called hospice earlier and was told someone would be in touch to schedule a visit. After Luisa left I got Nico from his room, telling him his mother wanted to talk with him. He settled on her hospital bed adjacent to a wall of photos of him and his mother. I sat on a chair next to him.

I shared with him my experience working with hospice, explaining the services they provide and

how his mother would benefit from increased support at this time. The conversation unfolded with Mary Beth commenting and asking questions as I added relevant information. I listened carefully to Mary Beth who was at once remarkably loving and generous toward her son as she spoke openly about how hospice marks the beginning of the final chapter of this journey for her. She said it could be a matter of months or it could be a matter of weeks before she dies. She encouraged Nico to ask for what he needs along the way. Does he want to meet with hospice folks when they come? Does he have questions about his past that his mother would be able to answer? She reminded him of the many friends who know her well and could answer questions he may have in the future.

Although he expressed little during our conversation, the hug Nico gave me when I first came to his room and the wave he gave me as I was departing, suggest he knows we are soon to experience a painful loss. How do you say goodbye to your twelve year-old son? You really can't.

— Curtis Grindahl
Client Services Coordinator

*Someone I loved
once gave me a box
full of darkness.
It took me years to
understand that this too,
was a gift.*

Mary Oliver

Photo credits: On page one is a photo Curtis took during a visit Mary Beth made to a cemetery in Olema. She wanted to find a place that would be natural and available for Nico to visit. On page two is a by photo Curtis titled *Filtered Sky*. On page 3 is a photo taken by George Ward titled *Lee Vining Creek in Fall*. On page four is a photo of Mary Beth taken near her backyard refuge where she met with many friends. On pages five and six are photos taken by Mary Beth's dear friend Travis Smith who traveled with her and Nico during the adventure in Spain and France. The first is from a hill town in France where they stumbled on a festival. The second is from an urban setting. Travis mentioned she was eternally trying to keep up with Mary Beth and Nico.

Coda

We celebrated Mary Beth's birthday on December 17, 2016. Two friends from Los Angeles, Amanda and May, drove up for the occasion. Mary Beth's brother Joel drove down from Sacramento. As with the "dinner parties" held from time to time, everyone made a contribution of food and libations. We all appreciated how much our dear friend enjoyed a good party. They were always wonderful events filled with laughter.

Mary Beth, confined to her wheelchair, was using a portable microphone that amplified her voice so she could engage in conversation, though her energy was limited so the conversations were short. There was wonderful food, good wine, cocktails, beer and a chocolate birthday cake. Mary Beth blew out the single candle, much to everyone's delight. Mary Beth definitely seemed to be enjoying herself. Clearly she received much love from those present. Hugs and kisses were in abundance.

On Monday morning, Carolyn, her dear friend with whom she had lived since moving from Los Angeles over four years ago, sent an email saying that Mary Beth had come down with pneumonia and was taking antibiotics as well as increased morphine to comfort her troubled breathing. The nurse from hospice visited, and a friend who'd recently joined the circle of supporters came on Tuesday and Thursday to do Jin Shin Jyutsu with her. It was sometime early on Friday morning Mary Beth took her last breath.

With Carolyn's alert that Mary Beth had died a number of friends came to be with Mary Beth and with one another. For the next three and a half hours we surrounded Mary Beth's hospital bed, sharing our grief even as we spoke of the joy we experienced

through our relationships with Mary Beth. Travis had spoken with Mary Beth about rituals that might be performed after her death. I know from my own conversations with Mary Beth about holding a memorial service following her death that this was not a subject she enjoyed discussing. But she did offer Travis enough guidance that we did in fact attend to Mary Beth this morning... applying oil to her feet and ankles, then washing hands, feet and face. Nico would at times join us. He picked up a wash cloth, soaked it with water, then touched his mother's face.

Travis told the story about showing Mary Beth a sari she'd bought in India, asking whether that might be suitable for a wrap after Mary Beth had been bathed. Mary Beth didn't especially like it until Travis said buying another would likely cost \$200. At that juncture Mary Beth said the one Travis had was just fine... we smiled at that, knowing Mary Beth as we did.

Five women washed Mary Beth's body and wrapped her with the sari. When I first saw her she seemed both at peace and remarkably beautiful. Mary Beth had asked Travis to take photos so Nico would have a record.

An interesting aside is the fact Nico's cat Felix, who had been carousing for weeks showed up the morning Mary Beth died. He soon found his way to her bed and lay resting against leg.

Mary Beth will be cremated the first week of the new year. Nico has expressed an interest in attending. A number of friends will join him. A memorial service will be held, likely in late January. Notice will be given as soon as arrangements are made so friends who wish to celebrate Mary Beth's life can make their plans to attend.



Mary Beth with the light of her life, Nico.