

Rebecca's Life with Treatment

How does one measure a second chance at life? Can any collection of medical tests begin to express the sheer joy and elation in a return to the living? It is my hope that by sharing a



Me celebrating Días de los Muertos in Oaxaca (Mexico)

comparison of life before and now with enzyme replacement therapy you will understand and celebrate the magnitude of what so many have accomplished in the creation of Myozyme, and why I feel I have been given a second chance at life. A life again, rich in achievement, vitality, participation and a promising future.

I remember a recurring dream during our eight long years of waiting for treatment. For me it was heaven for as long as it lasted. It went something like this...

“Once in a blue moon comes a night that takes me out of this broken body. In my night dream I am running. I can feel each capable foot push off the firm believable earth. I can hear the strength of my breathing in reassuring rhythm. I am jubilant in my returned memory of a body whole, firm and radiantly beautiful in its perfect cadence.”

When I look at this description I am riveted to the words capable, strength, jubilant, whole, firm, radiant, and perfect. Before Myozyme not one of these words could be used to describe me. I would have had to use the words

exhausted, racked with pain, extreme fatigue, undone, isolated, incapable, weak, and overwhelmed.

“Pompe’s disease for me was a recurring pattern of countless heartbreaking attempts to participate, contribute and achieve gone awry. A life meant for living that would deteriorate with a persistent tenacity. It would play out again and again across the canvas of my life. Spirited, enthusiastic and in love with life, still my most personal endeavors, hopes, dreams, aspirations, nothing would remain unscathed.”

What was my daily life like before I began Myozyme? “Think of birds....land birds, tall tree dwellers, low ground hoppers...I felt much like them. My territory was clearly defined. I dwelled in a world that resided exclusively above my waist and as high as my arms could reach. If I dropped something...it was out of my world. If it was above my head...there was no getting on a chair or ladder to reach for it. If I fell I could not get up. Once, my interests and enthusiasm took me in a myriad of meaningful directions. I went snorkeling in countless exotic reefs across the world. Biked rugged hillsides of fern embraced forests. For years I worked on a cruise ship and traveled the world. I shared a weaving studio and wove incredible rugs from a lost tradition. My textiles hung in the American Craft Museum of New York. My art traveled in gallery shows as

far away as the Netherlands. With Pompe's, I struggled to navigate a world that revolved around my bed, bathroom, kitchen, and only what resided above my waist."

May 31, 2006. After waiting eight long years of continuing physical decline my day arrived. There was absolutely no where else in the world I desired to be but in that white washed infusion center. I hold that day in my heart along with the most important and cherished milestones of my life. I never hesitated or feared that merging of hope and Myozyme. I can assure you I am struck with the same rightness every two weeks when I am fortunate enough to have Myozyme course through my veins. I feel that I am a cloud drifting into its rightful sky. Something holy, something necessary is being delivered to me. I marvel to this day, at that profound rightness.

With Myozyme I have returned to a life of cherished well being. I am more firmly present in my body, focused and capable. I experience a profound sense of enjoyment doing simple things that once racked my body with unimaginable pain. Such a renewed sense of self, as if I am running on high octane fuel, humming through my day, as opposed to dragging myself, exhausted from one thing to the next.

My muscles have new strength and integrity. I stretch my legs and am startled every time by the feeling of response and power. I am amazed to feel connected from my head to my toes instead of the many dead zones of unresponsive muscles and constant pain. I have spent the last eight years shuffling off to bed at the hint of night fall craving the relief of a prone position to alleviate the arduous work merely of supporting my body weight against gravity. Everything, for the last eight years, even the simplest task has been a marathon effort.

Since Myozyme, my husband begs me to call it a night. I wake up in a whirlwind of excitement, always the first one up, most days before dawn eager to begin my growing list of possibilities. I am for the first time in years making plans. Important commitments that I know in my heart and body, I can keep. I am remembering the "fullness" of being tired at the end of a busy fulfilling day, not the dreaded exhaustion I use to begin each day with.

"Life moves forward like a giant graceful wheel through all the seasons. Friends and family move closer to achievements and life dreams. In growing isolation my journey takes me disturbingly closer to more loss where parts of me die in increments everyday."



Me and my friends in front of one of our Murals in celebration of Día de los Muertos

I look at our calendars from the years before treatment. Most notations are for doctor's appointments and months on end that are empty and stark. Since beginning treatment with Myozyme I have returned to work full time, taught countless weekend workshops, traveled to several schools to teach one and two week mosaic intensives to high school students. I have designed and completed several major stained glass window installations.

For the past year I have directed numerous service groups in the creation of seven out door mosaic murals for our town. I have traveled extensively. My travels took me to new and unknown terrain as far away as New York, Monterrey, Oaxaca, San Miguel de Allende and Brazil. Before Myozyme the unknown always kept me close to home and familiar ground, an unexpected incline or curb was equally insurmountable.



One of my first collage paintings

"It's all just so many words. The fatigue, the pain so intense I could barely walk. My deepest struggle was having such a vital, passionate desire to live a life well lived. My optimism and desires were just as alive and intact as when I was healthy. The frustrations grew from having all the momentum and inspiration a heart and mind could hold, and a body that could not possibly deliver. More and more I was forced to reinvent myself. Let go as gracefully as possible to the ever growing list of what I could not do. Try and focus on what was still possible and be grateful for it."

Most recently I have begun to paint, a personal testimony of believing in my future. Painting was something I longed to explore but kept for the day I would be too weak to continue on with the more physically demanding art of mosaics and stained glass. My calendar is now full of ambitious achievements reflecting a return to a quality of life beyond my wildest expectations.

I feel compelled to include an excerpt I wrote last summer before Myozyme and shared on the GSD.NET. It carries the reality of living a life of steady decline, and the desire to hold on to the sweetness of life lived to its fullest. It is positive, courageous yet reveals the overwhelming knowledge that loss was inevitable. When I looked to my future I was not looking toward plans, goals or achievements...I was laying the ground work to meet death with courage and a full heart.

"My husband's family has a cozy cabin on a quiet lake. You can feel three generations of summer laughter mingling in the shadows and golden light across the water. Two years ago we swam in all that gleaming light! One day we boarded the motor boat. Out into the huge silent lake we sped. My husband taught our young son to steer and he was gleeful!!!! The boat threw arcs of water as we went faster and faster. I sat at the very front and closed my eyes. I wanted to drink it all in! The wind whipping our hair wildly, the force of summer's heat leaning across our cheeks. Our young son mastering and steering all that force. I kept thinking, remember this Rebecca. The feeling of speed propelling yourself as if flying across the open blue lake. Remember your son's gleeful laughter and your husband's pride. Take it all in so on the day you lie close to death in a body that strains to move you can taste the sweet joy of summer life with your boys.1` You can feel the sun lean against your cheek, hear your son's glee and feel your husband's pride. Remember, so you can leave this earth with your spirit flying."

So much can happen with an optimistic heart. Personally, I cannot imagine what my health would be like today without the insight and wisdom of Dr. Slonim. Following his diet and exercise program for the last eight years while waiting for Myozyme has, in my opinion, proved life saving.



Me and my friend before an altar

And now I cannot imagine my life without Myozyme. I feel my life is again brimming with possibilities and I love the mystery of it all! After years of my son imploring me to climb Indian Hill behind our home, to share the stunning view of our surroundings, we have done just that! Suddenly one morning after several months of treatment I just knew that I could now climb that hill. I found my boys and announced that I was ready to try. They dropped everything and we set out in a wave of excitement. It is difficult climb that goes round and round, steepy with every turn. When we reached our

my son took a picture of us as it began to snow! We were thrilled, as we shared the beauty of the landscape that unfolded before us, and reveled in the enormity of simply standing together on the top of a once insurmountable hill.

Was it only one year ago that I struggled to navigate life one day at a time? Here is the gratitude that fills my heart. I have returned to an active life that is rich in family, friends, artistic expression and the opportunity to reach beyond myself and make a difference in this world we share. I live life each day for the gift it is. I am truly standing on top of a once insurmountable illness living a life well lived and for this I thank the miracle of Myozyme.

Rebecca Brooks



Some of my Art Works I now can continue to work on