Reflections on My Double Lung Transplant

Dylan Mortimer

I was born with a respiratory disease called cystic fibrosis. It’s a deadly degenerative disease that had a life expectancy of 17 when I was born. There was not a lot of hope in those days for someone like me. I turned to art as a way to imagine. Not to simply escape my fears, but to own them and be honest with them. I began drawing and painting from an early age, and though the work did not directly have to do with my health condition, it framed much of how I saw the world. As time went on I continued with art, majoring in Painting for a BFA at the Kansas City Art Institute and in Fine Arts for an MFA at the School of Visual Arts. My work at the time had to do with ideas of faith, prayer and spirituality. I got married and had kids, both miracles for a CF patient like me, but my health began to worsen and I began evaluation for a double lung transplant.

At this time I felt it dishonest not to bring my health into the visual conversation. I reconciled that my disease was not all of me, but it had been a significant part. I started making work directly in response to my journey, and my experience spanning between trauma and joy. The subject matter I began to use were symbols of immense difficulty for me: bronchial trees, scars, iv bags, cells, and a variety of biological and medical imagery. I was drawing these images on thick paper to cut out. I had been using glitter in the previous work, and this seemed to make perfect sense with this new imagery. Transforming the trauma and difficulty into glistening, glowing objects of inspiration and hope. I began to see the parallels of glitter with disease. It’s dirty, gets everywhere, and people are afraid of it. Yet it transforms things. The stories of overcoming and victory are unlike anything. Glitter held the tension for me. Speaking to the unspeakable terror of living with a degenerative rare disease, yet offering hope in the midst of it.

So I adorned these objects and created collage paintings out of them. All bathed in glitter. And the glitter layered on top of itself in a baroque symphony of pain and joy. It was important to evoke that balance. Having a disease like this is terrible. Yet the triumph over it brings unspeakable joy. Much like the symbols I use. You wouldn’t wish them in themselves on anyone; scars, cells, pills, medical equipment. But those very things save our lives. It is both/and. But the triumph of living amidst all these challenges far outweighs the physical and metaphysical challenges.

I went on to receive a double lung transplant in 2017. I felt the best I ever have in my life for about a year and a half. I began to make artwork about what healing feels like... imagining how to visualize breathing fully for the first time in my life. But then quickly I experienced rejection and was listed for a second double lung transplant. I received a second transplant in April 2019 at Columbia University in New York City. In the most unlikely of ways, I was matched when I had less than a 1% chance to find a donor.

Receiving someone else’s lungs is an experience beyond words. It draws me again to the tension. It is tragic that two people died, and I mourn their loss with every breath. Yet I live because of them, and honor them with every breath. I did not earn or deserve new lungs... they were a gift. No one “earns” breathing! We receive it as a gift—whether through birth or transplant. And with this gift we celebrate. The way I celebrate is through visual art. It is my way to share that which is genuinely too much for words. But I can imagine and tell the story this way. My glistening symphony is my attempt to transform all this difficulty and pain into a celebratory party. I hope my story helps others to keep up the fight to see life beyond what is thought possible.

I'm fortunate not only to be alive but to create in this way. I have installed work in public and private
collections nationally and globally. I love to transform hospital and clinic spaces especially. As a patient I walked by too many blank hospital walls, or walls with stock art or neutral environments. Where are people more in need of inspiration, hope, and a sense of dignity? I have personally found hospitals and clinics to be some of the more undignified places. The neutral atmosphere often feels cold and impersonal to someone struggling. We need hope in those spaces. I aim to transform more spaces and have been very fortunate to be a part of that transformations in hospitals around the world. I aim to keep breathing, keep creating and sprinkling hope everywhere I can.

“The Congregation” by Dylan Mortimer.

“On My Mind” by Dylan Mortimer. Pictured with the artist, left, and Dr. Richard J. Barohn, right.