

Project Statement: *Patrizio* | 4-2-18

In December of 2016, Patrizio approached me in a Café. He's a former Chicagoan, now resident of Italy; former trader, now singer/songwriter; father of three and founder of a gene therapy firm searching for the cure of Thalassemia, a rare inherited blood disease.

Patrizio and I spoke in Italian about the many facets of his work as advocate for *orphan diseases*. Intrigued, I began a frantic investigation into the incredible world linked to his efforts, his son's illness and orphan diseases, called so because they affect small patient populations who are 'orphaned' by the pharmaceutical industry. I raced through a New York Times story written about his endeavor and listened to "One More Day," a song from his third album, *Orphan's Hope*. I discovered the beautiful vulnerability of a parent, asking for more time. I decided to participate in the orphan disease struggle the best way I could—with my art.

Patrizio was scheduled to perform in a music concert in Italy wearing a Versace jacket, gifted to him by parents who lost their child to Battens. He couldn't wait to perform in that jacket in January 2017, hoping to take and send a photo to the family in honor of the child. Unexpected snow in the south of Italy caused the concert to be canceled. I asked him to bring the jacket back to the U.S. so I could take 3-dimensional "photos" of him in the jacket and cast a bronze sculpture to give to the family.

The gifted statue was featured in a CBS news segment about their struggle, and shortly people began to ask for statues; some suggesting the cast metal sculptures be presented as awards for people making a difference in orphan disease research. The statues embody the story of the jacket and the stories surrounding Patrizio's research. The first Orphan Dream Award was presented at the Orphan's Dream concert "La Notte delle Malattie Rare/ORPHAN'S NIGHT" at Casa Cava, Matera, Italy, in December 2017 to Dr. Locatelli of Bambino Gesù Hospital in Rome.

To make a lasting object in cast aluminum, iron, or bronze, a series of transformations occurs. A mold is made from the original wax or plastic (3D printed) pattern, then the wax and/or plastic is melted and drained out of its ceramic mold. Molten metal is poured into the mold, and the shell must be destroyed in order for the sculpture to come into existence. In a recent review of the work, Chris Miller of *New City* wrote, "[Megan Euker] applies the latest technology in three-dimensional printing and fabrication to fulfill that most ancient function of figure sculpture: commemoration." The sculptures range from 3-18 inches in height and from stark white to charcoal black. Grouped together, these sculptures bounce between being bodies, ghosts, and shadows.

In Patrizio's words, "This is the parent of a child with OD. His clothes don't fit like they used to. He's a foreigner in every land. He wears his jacket like a military uniform. His hat has his rank. He's surrounded by thoughts."

—*Margherita*