

## 2018 Hope Babette Tang Humanism in Healthcare Essay Contest

### 1st place | Medical Students

#### Antoinette Esce

3rd Year, University of Rochester

The man was running. One hand on his wide-brimmed black hat, keeping it pressed to his head. His handmade linen pants pressed against his thin legs. His temporary Children's Hospital ID badge flapping in the wind against his chest. The scene was almost comical; it was dusk and he did not fit among the streetlights and cars and hospital parking lots. I knew this man. But I did not know why he was running.

Perhaps he was running to something. Maybe in search of non-hospital food or a bit of fresh air. Perhaps he was merely stretching his legs, which were otherwise bent in a seat next to a hospital bed. Perhaps he was running away from something. Maybe from the overwhelming hustle and bustle of a complicated life he had chosen to avoid. Or maybe from his child, in the tower behind him, who was slowly dying of cystic fibrosis.

---

I knew this man, as well as one can come to know the father of a new patient. His son Jonah is ten years old, gaunt and pale, with fingertips and toes swollen from chronic hypoxia, reminding me of the black olives I shoved onto my fingers as a child. He is cheerful and doesn't complain, except to confirm his mother's advocacy about his thirst or discomfort. His large and loving Mennonite family, speckled with cousins who have lived and died with cystic fibrosis, come in and out of his room, reading with him, cheering him up, and diligently providing the ritual of chest therapy every hour without fail. They know that Jonah will eventually die from his lung disease and they do all they can to ease his suffering.

Still, Jonah had presented to our emergency department in respiratory distress and an oxygen saturation half of what it should be. His family gets free medications from a different hospital, but can never make it to Jonah's follow up appointments. They don't believe in accepting government assistance, because their life revolves around their religion and they want it separate from the state. Their community is still paying off the bill from his last hospitalization.

The experienced pediatric pulmonologist says, "this is what cystic fibrosis looked like when I started fellowship." The care coordinator is distressed, because these patients can live well into middle age with aggressive therapies. The provider team is torn between the out of pocket expense of a now questionably beneficial, conventionally aggressive treatment regimen and the unnerving complacency of a more pragmatic approach. The social worker reflects that "if this was any other family, we would have already called child protective services."

The facts of this case are straightforward. We're looking at a ten-year-old Mennonite boy with severe cystic fibrosis, who has not been receiving the standard, rigorous, inpatient treatment protocols, presenting in respiratory distress. We're all looking at the same thing. But what did each of us see? Some of us saw a helpless young boy, born into a world that he didn't choose, whose life and opportunities had been unnecessarily taken from him by his community. We saw a negligent family, letting their child die from a terminal, though treatable disease. We saw a world and a culture that we couldn't begin to understand, a set of values that we rejected as immoral. How could they put their desire for a simple life above the health of their child? It was wrong.

---

Stopped at a red light outside of the hospital that night, watching Jonah's father running along the side of the road, I realized that I saw something different. His stance was resolute, his face was sad, he looked tired. Maybe he wasn't running from Jonah's illness or the hospital. Perhaps he was running away from us, our discomfort, and our judgmental stares.

---

I had been conflicted that afternoon. The narrative of neglect was convincing, but it didn't seem to fit with the devoted and loving family or the happy child for whom I had spent all day caring. How could they neglect him without scarcely leaving his side? Was he malnourished from an incapable family or because his pancreas was shutting down? Was his lung disease so severe because of stubborn parents or because the cystic fibrosis that ran in his family was particularly deadly? Was his family's approach to this illness truly wrong or was it just different? Didn't they have the right to treat it with culturally sensitive medical care?

I sat with Jonah and his family for a while. I saw a well-worn book at his bedside table. He told me that it had belonged to his many siblings before him. It comforted him. I saw his family's innocent fascination with the helipad outside his window. It made Jonah laugh. He told me how he wanted to go back to his farm, to his pony, to his home. I saw that he knew he was sick. I saw his mother's face set in resigned sadness, but laced with pride for the brave and mature boy in front of her. I saw a loving family, gracefully coping with tragedy. It was beautiful.

---

The red light had turned to green. Jonah's father turned a corner and was gone. I wondered what everyone else, in all the cars around me, thought about him, in his foreign garb and robust beard. Stranger in a strange land. Mennonite man on a medical campus. Henry David Thoreau said, "it's not what you look at that matters, but what you see." But where was the truth in what we saw? I don't know. Probably somewhere in the middle. Somewhere between neglect and beauty. Somewhere hard to find.

**2018 Hope Babette Tang Humanism in Medicine Essay Contest**

**1st place | Antoinette Esce**

I returned to the hospital the next morning, no surer about what I saw, only confident that there were many ways to see it. I went in to say hello to Jonah's family and handed them walking directions to a nearby park. "I hope you see something beautiful the next time you go running."

*Editor's note: The patient's name and other details have been changed to protect patient privacy.*

---

For more winning essays from 2018 and previous years,  
visit The Arnold P. Gold Foundation at [www.gold-foundation.org](http://www.gold-foundation.org)