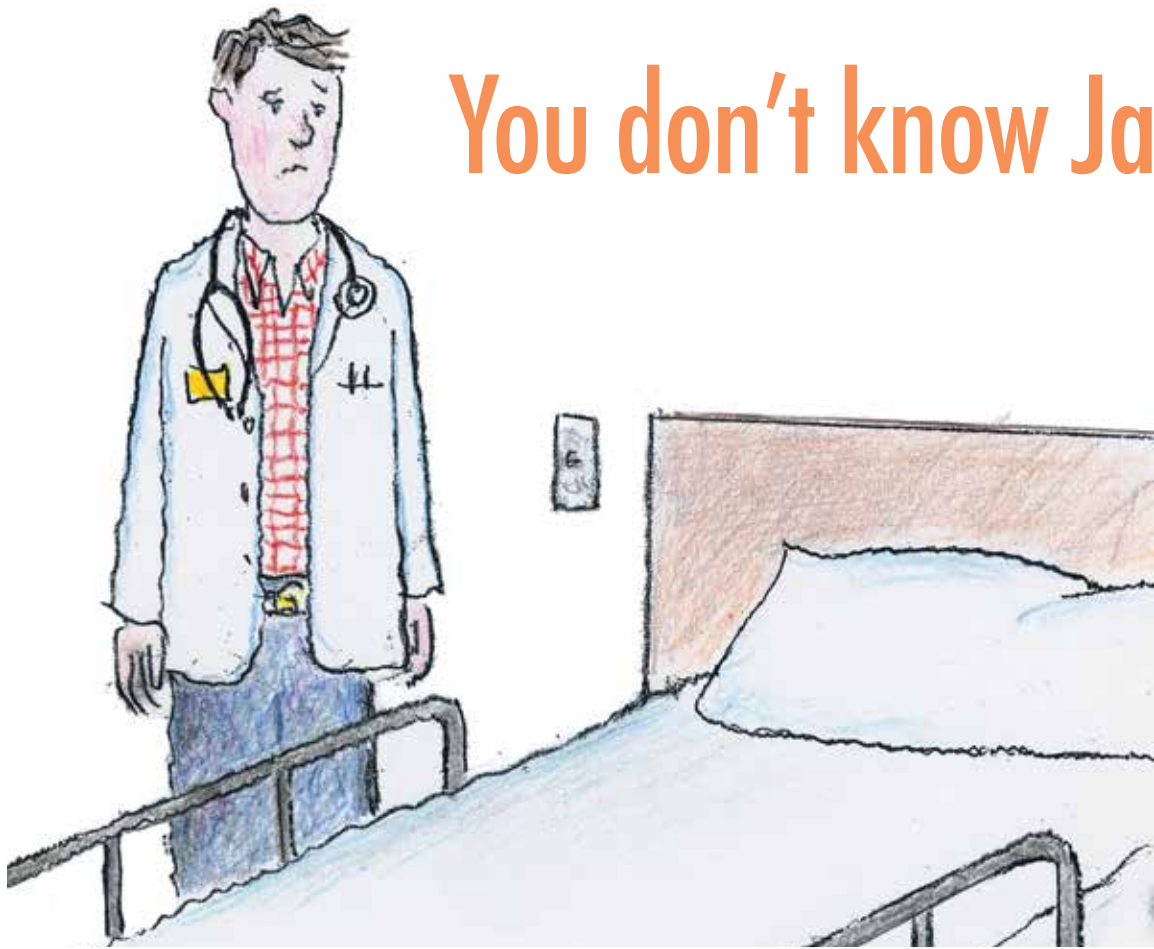


# You don't know Jack



## Jonathan M. Bekisz, MD

Dr. Bekisz is a recent graduate of New York University School of Medicine.

**April 6, 2015**

**Y**ou don't know Jack, I realized as I walked into the four-bed patient room on the afternoon of my first day on the pediatric hematology-oncology service. You don't know anything about him, and yet you know so very much more than he knows and would likely ever want to know, I thought to myself.

I knew his differential diagnosis, Glioblastoma multiforme (GBM) of the spinal cord with possible metastasis to the cerebral cortex.

As I caught my first glimpse of the young man confined to the hospital bed, he was completely oblivious to the terrible predicament in which he found himself. He sat there, nearly fully paralyzed from the waist down, intensely and understandably frustrated, knowing full well that something was not right, yet totally unaware of the unbelievably

cruel hand he had been dealt.

We didn't speak much that first day, little more than simple introductions and my offer to spend some time hanging out, talking about sports, food, and other things that might interest a 15-year-old boy.

Day in and day out, Jack sat alone as tests were done, surgeries were performed, and discussions about his condition were held among myriad physicians responsible for his treatment. I wasn't directly involved in his care, but it was a quiet afternoon on our unit and his story stuck with me from the moment I heard him presented during that morning's sign-out.

During our initial conversation, I felt myself walking on eggshells, so much so that I could almost hear an audible crunch with every word that came out of my mouth. I knew this dark and horrible secret, and yet there I stood, a smile on my face, asking him what hockey team he liked. In my short white coat, symbolic of my status as a second-year medical student, I was fully aware of the fact that I could do virtually nothing of any real therapeutic benefit

for Jack. Don't talk about his diagnosis, I told myself over and over again as I awkwardly sat down in a chair at his bedside. I tried to initiate a conversation, but Jack politely refused. He had physical therapy coming up soon, and he simply wanted to get it over with. Still, he thanked me for the offer.

Encouraged that he hadn't completely shut me out, I told him I might stop by again the next day.

#### **April 7, 2015**

When I found myself with some free time before rounds began the following morning I went to visit Jack. It was impossible to drive his story, with all its horrible, inequitable tragedy, from my mind.

My introduction was less awkward the second time, and Jack was in a remarkably upbeat mood for someone facing such adverse circumstances. We eased into a conversation, and before long were sharing thoughts and opinions on everything from local pizza, on which I offered a rousing endorsement of my favorite parlor, to pastimes, passions, and his thoughts and feelings about his current medical condition.

He hated the hospital food, excelled in biology, loved the Montreal Canadiens, and wanted nothing more than to walk out of the hospital and go back to his home in New Jersey. Jack played goalie for the junior varsity ice hockey team at his high school, which won the most recent state championship. He was also an avid and skilled scuba diver, and on his 16th birthday, coming up in October, he was planning to become a licensed pilot.

He was a regular teenage kid, a high school athlete from New Jersey much like I had once been, with regular teenage interests and dreams. It was this realization that made confronting him exponentially more difficult. Jack was no longer the "15 yo M s/p laminoplasty w/no significant PMH who presents w/a suspected GBM of the spinal cord w/cortical mets discovered after workup for several weeks of difficulty ambulating." He was Jack the high school freshman, A+ student, hockey player, and soon-to-be pilot who could very well have his bright future cut irreconcilably short by some rare and horrible disease that would ruthlessly run its course while paying no mind to who, when, or how it hurts in the process.

#### **April 8, 2015**

After two days by his bedside, I felt myself becoming very invested in Jack's case, despite the fact that when it came to his actual medical care I was little more than a spectator. I wanted to help him by doing anything I could to brighten his day.

The gravity of his diagnosis would hit me from time to time. As I dwelled on the inescapable reality that was his prognosis, I would recall the fact that he still had no idea what was wrong with him. I'm sure he had suspicions, perhaps even fears. But if he did, they were repressed by an absence of any desire to accept the impossibility of facing his own mortality, and manifest instead as a steely resolve to fight back against this invisible specter that had the audacity to interfere in his life.

I struggled to imagine what it would be like for Jack when he learned about his diagnosis. He clearly had the intelligence to understand the gravity of his condition. Yet, with so many things happening at a rapid rate, and such a great deal still to be learned, his parents, knowing their son far better than anyone else, decided to wait for what they felt was the most appropriate moment to broach the topic with him.

It hurt to listen to him talk about walking again, about going home, about getting his pilot's license. I vacillated between wanting to rally behind his resolve and determination, and worrying that in doing so I would be setting him up for even greater emotional trauma when he eventually learned his diagnosis—trauma that I would no doubt attribute to by encouraging him to prop himself up on dreams that in all statistical likelihood were nothing more than fantasies birthed from ignorance.

It was anything but fair for Jack, a theme that had become all too common in his life.

Jack had been in the hospital for several days, and his care team was actively working to get him transferred to a specialized children's hospital in New Jersey where he could receive daily rehab as well as transportation to the proton therapy center where he would be treated. For some unknown reason securing a bed for Jack was proving difficult. When a bed was finally reserved, it was a two-day wait, and conditional in that it could be given to someone else. My frustration grew exponentially with each hour that Jack remained with us. Was there any patient out there more deserving of that hospital bed?

#### **April 9, 2015**

When I arrived on the morning of my fourth day on the service, I learned Jack was to get a bed at the new facility one day early. He was set to be discharged within the hour. Before I could stop by to see him, Jack's father came to the nursing station to find me. Jack not only wanted to say goodbye, but was hoping I could give him my cell phone number so we could stay in touch.

I had spent much of my time on the service attempting

to bring some small sliver of joy to Jack's life, but by asking to stay in touch he had given me what was without question the most rewarding moment of my medical career.

I happily wrote it down for him, wished him all the best, and asked him to keep in touch. Several hours later, Jack texted me to say he had arrived at the new hospital, and was extremely excited to start his rehab. I would be hard pressed to recall a time in my life when I have ever received a more meaningful text message.

### Late April, 2015

Jack and I had kept in touch periodically since April 9. His rehab was progressing, and he was undergoing proton therapy to treat the tumor.

I didn't know how much he had learned about his diagnosis, if anything, and I dreaded the day he would finally learn the whole story.

I sometimes hesitated to reach out to him, because I worried about how learning of his diagnosis would affect his perception of the medical profession, his care team, and me. Would he hate me for keeping this from him? Should he? Am I selfish for even worrying about his perception of me given the dire straits in which he finds himself?

The gravity of his diagnosis still hits me from time to time. I wonder how his parents put on brave faces each day, sit by his bedside, and provide nothing but love, encouragement, and positivity with the weight of the world perched squarely on their shoulders. How can they listen to him talk about walking again, about going home, about getting his pilot's license without their hearts breaking to the point where they can no longer stand to even remain in their son's presence? To place myself in their shoes is quite simply an impossible task.

I am not an emotional individual; I never have been. However, Jack's story is one that will never cease to affect me in ways I would otherwise consider uncharacteristic of myself. I recognize the danger in becoming too involved with a patient, of investing too much, and running the risk of getting hurt. But, I believe there is value in that.

I believe there is value in caring so much that you make yourself vulnerable. I believe that these types of experiences provide the most poignant reminders of why I pursued a career in medicine. They keep me humble, they keep me compassionate, and they keep me human.

### February 10, 2016

Jack passed away January 16, 2016, after a nearly year-long battle with what is arguably the deadliest and most aggressive cancer known to man.

In the months since my pediatrics rotation, Jack and I remained close, and I was fortunate enough to be able to visit him several times. We traded stories, and talked about all the city had to offer; with his treatment Jack was healthy enough to enjoy some of its sights and attractions. I tried to convince him to try my favorite pizza place.

We never spoke of his desire to get his pilot's license. Instead, we talked about how, through remarkable grit and determination, Jack regained the ability to walk near the end of the summer!

Despite the fact that the majority of our interactions played out in various hospitals, our conversations had a way of almost never touching on the gritty medical details of his disease. Jack eventually used the word cancer when speaking of his illness, but never with any fear or trepidation. His courage was a testament to his character.

One evening in the middle of January, I received an email from Jack's father asking me to call him. It was late by the time I received the message, so I opted to phone him the next day. The following morning, as I sat at my desk studying about T-cells and B-cells, Michaelis-Menten, and Krebs, something about that e-mail just didn't sit right. I typed Jack's name into my web browser and found myself staring at his obituary.

His funeral was later that very morning. I caught the next train out of Penn Station, and arrived just as the procession was making its way out of the church. I joined the group traveling to the cemetery for his interment.

The outpouring of support for Jack during his battle with cancer and the crowds of people who attended his funeral services was testament to the impact he had on the lives of so many.

When I got back to New York later in the evening, I ate at the pizza shop about which I had so often pestered Jack.

I am now nearing the end of my third-year of medical school and beginning to prepare for the next phase of my career. While I have had many meaningful and fulfilling experiences during my time on various clinical rotations, the relationship I was fortunate enough to form with Jack will forever stand out, singular in its poignancy, tragedy, and ability to leave me feeling so very grateful. Grateful for everything that he taught me. Grateful for the chance to have had an impact on his life. Grateful for the even larger one he had on mine and grateful for the opportunity to be able to say I know Jack.

The author's address is:

564 First Avenue, Apt. 19Q  
New York, NY 10016