Transplant team:

This is a very hard communication for me to write, but necessary. I took a few days to think about it before I typed this out. However, I know this program prides itself on taking constructive critique & values open communication, so ultimately this why I'm writing this.

Thursday, June 16, 2016 was a very tough day. Not the first of course, but one of the more concerning ones. I was dipping to 85 with my oxygen levels walking 25 feet to the kitchen for water, 30 feet or so to the main floor bathroom from my den. This was with my Niov set to 250 ML, the highest it would go.

My primary caregiver didn't even have to push me to get it checked, like she did sometimes in the past. In the past, I sometimes waited longer before seeking treatment because I thought an ER doc would chalk it up to anxiety or decide it wasn't a big deal. Sometimes that had happened with previous ER visits when I was living in New York.

I went to my local ER. They triaged me & took me back to a room in short order. The ER attending there knows my pulmonary doctor. My pulmonary doctor happened to be on call so the ER attending paged her immediately.

My pulmonary doctor came over to check on me. She said she was worried & would prefer to call down to my center & speak with my transplant doctor. She wasn't sure what the root of my problem was. She decided it best not to take chances. She wasn't sure they could do as much to help me there so she said she was going to have me transferred.

Both doctors agreed that I should be immediately transferred down to the center for care. I was grateful to them both for their quick action & teamwork & also knowing me so very well.

I eventually was transferred & settled about 3:30AM on Friday morning. Dr. XXX rounded later that day. Immediately, they began asking me for the films of the CT I had in the ER. I explained that I hadn't been given the films before I left. I will be honest, I often joke about being my electronic health record (EHR), but this time I was feeling so God awful because it was so much work to breathe I didn't even think of asking for a disc.

My backup caregiver was with me. I explained that my primary caregiver was at home but would be unable to get the films & drive down here. Plus the fact it would be an over 120 mile round trip for someone. I asked Dr. XXX to send for them yet they seemed to resent having to do that. After that, they seemed a little hurried and dismissive but I was too tired & too relieved I was receiving care at my transplant center to challenge much.

My transplant doctor called me Friday night. I felt better talking to him because I knew he always has a plan. He said he requested some tests to be run to rule out pulmonary hypertension & some other things that could be possibly causing these problems. He told me he was going on vacation & I said that was perfectly fine. I meant it but I really appreciated he took the time to tell me himself.

Saturday & Sunday were hard. Dr. XXX came in & each time they asked some questions but seemed to be missing the mark on things. I explained some things to them about my history with LAM but they seemed to question & disbelieve the reason I had a past surgery & asked me what a PeComa was. I told them that researchers had told me that it was a rare tumor related to LAM & TSC (which is true) I told them I didn't remember the type exactly that it stood for, but that it had been giving me serious health issues & that's why it was removed. I was kind of questioning why they were asking me about estrogen & tamoxifen treatments, but that's why I explained this history.

I did try telling them more than once, my case differs from classic forms of LAM and even some cases of TSC LAM because I have underlying asthma. I also have a heightened albuterol response (as a result) which is more uncommon in LAM. They seemed to dismiss that until Sunday when they mentioned that they had wondered why I had such a strong response to the steroid.

While they made the right call on the steroid, I felt they were tone deaf to many other concerns during my stay & when I told them about other concerns leading up to it.

This included the complaints I had mentioned to both my transplant NP & doctor about my decreased exercise tolerance & stamina over the past few weeks before my admission.

Dr. XXX really seemed to dig in when I asked them any questions about outpatient pre-transplant maintenance rehab. I wanted to ask them about this because I know my services back in my area are limited & I wanted a maintenance program more geared & experienced with transplant.

They basically made me feel stupid and bad for doing so well, saying there was no way a facility would take me (meaning a rehab) & to just go home. They started talking discharge before the breathing tests were ordered. In fact, they wanted to kick me out Monday, but I felt better & knew my caregivers wouldn't be available to pick me up until Tuesday.

They ordered the ECHO but never reviewed the results. They took cultures but never informed of me any of those results except to say that my flora had potentially changed. They wanted to start me on Bactrim. I agreed to this because I agreed with their point that sometimes my Zithro regimen could potentially mask a problem.

Dr. ZZZ, (who I saw on Monday & Tuesday) in contrast did review most of my test results with me & listened to my concerns. This doctor seemed to follow an approach & plan similar to my transplant doctor which I was relieved for.

This doctor also picked up a spike in my creatinine & did an additional test to be sure it wouldn't be something of concern. I felt much calmer, in better hands & listened to the last two days than I had when I came in. I didn't think to ask at the time about the cultures. I just was asking this doctor for a simple plan to follow until my transplant doctor returned.

I had no PT from Friday until Tuesday morning. I did walk when I could, but Monday I was still too weak (especially to drag around an IV pole during a fluid test to check my creatinine) so took a few short walks after that test was done.

Because of Dr. XXX's attitude towards me, I worried about my walk test & PFT the whole time. Neither of which happened. I thought I might fail & set back my score because I was responding well to the steroid. I don't know that any patient should ever have to feel such a ball of nerves over tests they take repeatedly, but I certainly did.

Dr. ZZZ understood better where I was coming from with my therapy questions & listened. The doctor didn't seem convinced that therapy at the center might be in my best interest but this doctor did tell me to follow up with my transplant doctor on that & at least made sure I got one day of PT to address these concerns.

My social worker provided me information about programs near me as well as the number to the outpatient program. I asked for this information because I feel even though it's out of pocket for me, it's in my best interest now since my oxygen demand for exercise is becoming so high. I don't feel safe just exercising on my own at the community center anymore. I'd rather have access to high flow oxygen if I need it & some monitoring although I know I don't need much. But most of the programs in my area are geared to the over 60 set and not to young people & that's why I also wanted information about the program.

I was made to feel stupid for advocating for myself. This eroded my trust in the transplant process temporarily. My caregivers & parents were concerned that I was having to work so hard for care in a place that generally takes such great care of me. I felt like I had made a mistake, like I maybe should have stayed at Anderson instead.

That type of insecurity didn't make me feel any better as I've had nothing but trust in this program to date with every decision. It seemed to Dr. XXX that I shouldn't even have come. I pointed out to them that two doctors requested I be treated down here.

They informed me that my insurance was questioning my transfer. This gave me an added burden I shouldn't have to worry about. I followed up with my insurance case manager after I got home (she called me) & she said she'd look into that but she had no notes about that.

I don't blame Dr. XXX for the reaction to the Bactrim, but I was upset when my local PCP reviewed my hospital records of the culture & told me there weren't signs of an active infection. I was led to believe there was by them & that's why I was being given the antibiotic in the first place.

The point of this is (if at all possible) I would humbly request I not be seen by Dr. XXX in the future during the course of any further hospitalizations as a patient.

If I must be seen because they are the on-call or rotating transplant physician, I understand that but request a plan be made that they adhere to strictly. Or to have limited interaction with them in the future. I felt I was unduly stressed during a time I was already gravely ill & vulnerable.

I was made to feel invalidated for advocating for myself & asking questions & being proactive. My transplant doctor, Dr. ZZZ, or any other transplant team members I've interacted with so far have never make me feel this way.

I'd make the same request of any doctor who I felt impacted my care adversely. I had similar concerns with another doctor. Those concerns led me to stop my care with them a few years ago. It's just not something I tolerate.

I appreciate your consideration of this request and the chance to be heard.