Timothy (Timo) initial post 9:00 pm 12-07-2014

This document can be read by anyone with a link. **Please only share with others who know Timothy F.**
https://docs.google.com/document/d/1-K5hei9J6UmQ2BfJ7_RxA9jCPkhZzknA7wziA3x4xGE/edit?usp=docslist_api

Timothy was staying at my place in San Francisco. He originally came earlier than originally planned to stay with me while my spouse JD is being treated for a collapsed lower left lung at CPMC.

He woke me at about 4:30 am December 7 complaining of pain in his chest, he was holding his right chest, but was concerned that it was his heart. He told me he was feeling clammy and the pain had started a couple of hours ago but the pain had increased dramatically in the last few minutes. He asked me to phone 911, which I did. The paramedics came within 5 minutes.

They assessed him, and took him to the ER at Davies Medical Center (about 5:00 am). He called me (at about 8:00 am) to tell me that his right lung was partially collapsed and that they would admit him. They later took him to CPMC and he called me again (1:45 pm) to say he was in the MSICU (Medical Surgical ICU) and headed for surgery, (just 25 feet from JD's room). I went in to see him in the MSICU, before he left for surgery. The nurses recognized me from the weeks that JD was in the CCU & later MSICU and they were very kind to explain that he would be placed in the CCU after surgery. They also told me the surgeon's name is Dr. Glenn Egrie.

I found out from Joel that he was out of surgery and all was well at about 4:30 pm. He told me what the surgeon said:

Diagnosis = spontaneous pneumothorax caused by a congenital ruptured bleb.

Prognosis He'll be in hospital for 3-4 days and then & 6 weeks recovery at home.

At the bottom of this document is some research into Timo's condition and standard of care.

He is currently in CCU, Room 325. They will keep him asleep overnight and wake him in the morning.

- Naomi CopperJet

Current Update - 7:15 pm Monday, Joel 12-19-2014

Timothy had the tubes that were draining fluid from his lung and lung area removed today. He is fully “unhooked” from IVs and all medical devices. He expects to be leaving the hospital some time tomorrow.

Current Update - 12:45 pm Monday, Joel 12-15-2014

Dr. Wendy Zachary visited Timothy today. She showed him the CAT scan, and it shows that the problem is that the tubes are not reaching where the unwanted fluid and air are. So, they will add a new tube to reach those places. Also, he has a cracked rib, which will be repaired later, if it’s deemed necessary. She said no flying to Kansas before the holidays; any time before New Years is unlikely. He will need the IV antibiotics for some time, most likely in a skilled nursing facility.

Current Update - 4:15 pm Fri., Naomi 12-12-2014

Timo was just moved to another room to increase the level of quietude. The new room number is 410-A. He has a window and NO roommate! When I visited his friend John was sitting with him. p.s. from Joel: His phone number in room 410-A is 415-600-8003. He is also using his cell.

Current Update - 12:30 am Fri., Joel 12-12-2014

Timothy has moved to Room 438-A. They have lowered the dose of IV Dilaudid and are substituting oral Percocet instead--with the goal to be off Dilaudid altogether when he leaves the hospital. The chest tube drain is no longer in suction mode. He will have to wait until a day or two after the chest tube drain is removed to leave the hospital, so they can see how he does without it and give him an additional x-ray. But, he isn't ready yet to have the drain removed (still too much fluid being collected).

Current Update - Naomi Thurs., 12-11-2014
Timo had a problem yesterday afternoon and the chest tube drain was put back into suction mode. It was collecting around 100 mmL of fluid now. The doctor wants it closer to 30 mmL. He was in suction mode for 12 hours until earlier this morning. They removed the pressure bandage on his neck this morning too.

Yesterday he walked to the nurses' station and back and he is hoping to do that again today. He is still in pain and his base level of pain med is higher.

The hospital is using back-up power this morning because of a wide-spread power outage in San Francisco from Downtown to Pacific Heights.

Current Update - Naomi 8:30 am Tues., 12-09-2014
Timo is still in the CCU as of 8:30 am today. More later ...
[12-11-2014] Timo was moved to Room 434-A on Tues. at about 9:30-10:00 am. You can call or text him. He would like to have visitors.

Most Current Update - Joel 2:40 am Tues., 12-09-2014

The hospital plan on Monday evening, announced around 10:30 PM, was to transfer Timothy to a regular hospital room (the ICU nurse Carly said he is "too healthy for us"). The final step in preparation for that was to remove the line feeding into his neck that was used for blood transfusions on Sunday. The line was removed, but it didn't stop bleeding for about 45 minutes (very slight bleeding), so the nurse Carly stayed with Timothy, putting gentle pressure on a gauze on his neck until it was OK. But, when they transferred Timothy to the bed to make the move to the regular room, he started bleeding again, so they decided to keep him in the ICU overnight to be safe. I just called at 2:30 AM and he has been stable, good vitals, etc.

The plan now is to do early morning labs and if they are fine, he will be transferred to a regular room. The room he was supposed to go to was 644B, but with the delay that could change. If it is 644B (on the 6th floor in the same building), his room phone number will be 415-600-8200. The nurses' station number will be 415-600-3644. Again, the main hospital number is 415-600-6000.

More generally, he has been doing well, but still needs Dilaudid for pain, which he can self-administer. Nurse took his blood sugar, which is normal. Ate a *very* little bit of a hummous/veg/bread meal.

Not passing urine or BM yet (if no urination by AM, and his bladder is full, they'll help that with a catheter --hopefully, one-time use).

Update - Naomi 4:10 pm Mon., 12-08-2014
First saw Timo at about 9:00 am today, he was awake, but still intubated and on ventilator support. We talked a bit with him writing comments/questions and me talking. When I came back about two hours later, he was off the ventilator and the tube had been removed. He spoke a little, and his voice was scratchy. They were still not allowing him to drink yet. He a was very evidently in pain, but he didn't say anything about that. I also came

back to see him at about 1:30 and talked a little more with him, they had allowed him water to drink and he was looking perceptibly better. He said he was in a lot of pain and very tired.

Update from Joel Federman (joel.federman@gmail.com), as of 11:20 PM 12-07-2014:

At hospital with Timothy. He is doing well. He is being kept asleep overnight and they will attempt to remove the intubation in the morning. All his vital signs are good. His nurse's name overnight is Maura. His respiratory therapist is Eric. They are both quite good and attentive. Loukas was here visiting as well.

The surgery was the more minor kind of those mentioned above: incision through his right abdomen (no cutting open the chest involved), using the VATS (video-assisted thoracoscopy) approach.

He has opened his eyes a few times, responded to questions and been able to squeeze hands.

A bit more detail from Dr. Glenn Egrie, the surgeon who operated on Timothy: The operation was completely successful--he removed the ruptured bleb, which was what caused the bleeding and the partial lung collapse. He expects a full recovery to "completely normal" life, with "no long-term issues." Hospital stay is expected to be 3-4 days; one day in ICU and hopefully transfer to a more regular room tomorrow. 6 weeks recovery after that.

11:00 PM: Dr. Jason Greenberg, the anesthesiologist who was with Timothy during surgery, stopped by. Timothy lost a lot of blood in the process and had to have 4 units of blood during surgery (more than ½ the blood in his body). But, once all that was stabilized, all went well. All vital signs look good. His expectation is that once the intubation is removed tomorrow, Timothy will be able to get up and into a chair. The incision usually causes a lot of pain, especially in the first four days, so it's expected significant pain meds will be needed.

11:10 PM: They turned Timothy and he woke up. He was able to hear that all is OK and that his mother/family is fully up to date and that his mother wants to fly out to help him recover. He was also able to write, and made sure that the Gonpa was contacted.

Spontaneous pneumothorax caused by a congenital bleb.

Google research results follow. (from Naomi CopperJet)

pneumothorax
http://www.chest-surgery.com/disease-info/images/pneumothorax/Pneumothorax.pdf

http://en.m.wikipedia.org/wiki/Pneumothorax

Primary Spontaneous Pneumothorax
http://ghr.nlm.nih.gov/condition/primary-spontaneous-pneumothorax :

> Primary spontaneous pneumothorax is likely due to the formation of small sacs of air (blebs) in lung tissue that rupture, causing air to leak into the pleural space. Air in the pleural space creates pressure on the lung and can lead to its collapse. A person with this condition may feel chest pain on the side of the collapsed lung and shortness of breath.

Blebs may be present on an individual's lung (or lungs) for a long time before they rupture. Many things can cause a bleb to rupture, such as changes in air pressure or a very sudden deep breath. Often, people who experience a primary spontaneous pneumothorax have no prior sign of illness; the blebs themselves typically do not cause any symptoms and are visible only on medical imaging. Affected individuals may have one bleb to more than thirty blebs. Once a bleb ruptures and causes a pneumothorax, there is an estimated 13 to 60 percent chance that the condition will recur.

Congenital bleb
http://accesssurgery.mhmedical.com/content.aspx?bookid=427&sectionid=40372731
Most patients with blebs are without significant underlying lung disease. Pathologically, bleb formation occurs secondary to mechanical stress from increased intrathoracic pressure in lung tissue that is predisposed to deformation by congenital weakness of the connective tissue.

Blebs, bullae and spontaneous pneumothorax
http://cirugiadetorax.org/2012/02/08/blebs-bullae-and-spontaneous-pneumothorax/

Description & Treatment
http://www.sages.orgthoracoscopic-resections-and-pleurodesis-forTimothyiseaseisease/

Treatments

http://cirugiadetorax.org/2012/02/08/blebs-bullae-and-spontaneous-pneumothorax/ :

How is this treated?

Simple (or first-time) pneumothorax

Oxygen therapy - traditional treatment for small pneumothorax in asymptomatic or minimally symptomatic patients was oxygen via a face mask or non-rebreather. Much of the more recent literature has discredited this as an effective treatment.

Tube thoracostomy (aka chest tube placement) – a chest tube is placed to evacuate air from the thoracic cavity, to allow the lung to re-expand. The chest tube is initially placed to suction until the lung surface heals, and the lung is fully expanded. After a waterseal trial, the chest tube is removed.

Recurrent pneumothorax / other circumstances;

Blebectomy via:

VATS (video-assisted thoracoscopy)
Open thoracotomy or mini-thoracotomy

As we have discussed previously, the VATS procedure / open thoracotomy and mini-thoracotomy are not really stand alone procedures but are the surgical approaches or techniques used to gain entry into the chest.

http://en.m.wikipedia.org/wiki/Thoracotomy

- Naomi CopperJet (copperjet@yahoo.com)