Slackware developer Patrick needs your help acquiring penicillin and information about the disease Actinomycosis.

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Patrick is seeking out to the Linux community for anyone with relevant knowledge about the rare disease Actinomycosis. He is currently off his job and expects to be so for a few more weeks. He is very eager to get back to work quickly. Help him if you have the knowledge.

- PAT-NEEDS-YOUR-HELP.txt

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Tuesday, November 16, 2004, 10:43

"Last post?"

Hi folks. If you're reading this, I thank you. Perhaps you could play in bringing about the miracle that I desperately need. I like to apologize for the lack of updates lately in Slackware stable... I know there are a few outstanding issues that need to be addressed. However, I've been too sick to work for a couple of weeks now I am away from my computers and at my parents' house in Fargo, North Dakota where my only online access is through an AOL dialup. I've told only a select few people about what's going on thinking that the internet at large to know about this, that I'd get it taken care of and get back on track without a major problem. Now, I'm hoping that this will get seen by a lot of people and that if it hits Slashdot, a kind medical geek will help save my life.
I've generally been a pretty healthy guy. Nobody I know would characterize me as a hypochondriac by any stretch, so when I raise an alarm, it tends to be for real. I'm going to give a timeline and run through all the symptoms I've had (so if that sort of thing grosses you out, you can stop reading right now). For the rest of you, here goes. This is going to be long, but hopefully somebody who can help will read it...

This all began quite some time ago, perhaps as long ago as May of 2001. I was preparing Slackware 8.0 for release and working really hard. A pain developed in my shoulder, and (too busy to do anything about it right away) I ignored it and continued to keep working. It got to be pretty bad and one afternoon in early June I was rushed to the emergency room at a hospital in Concord, California. I was sweating, feverish, with a weak pulse of around 50, experiencing chills and seeming to be on the verge of passing out. The doctor who saw me did a chest X-ray and didn't think it was too unusual. I was told it was probably bronchitis and was sent home with a prescription for ciprofloxacin which mostly cleared up the problem. Still the pain in my shoulder seemed to vague. By mid October of 2001, I was in bad shape again. My parents asked me what I wanted for my birthday and I told them some more Cipro. I found someone who was able to help me out with a 60 day supply, a task as this was right after the infamous Anthrax mailings (newspapers were running articles about Cipro and people were trying to horde it). I finished the two month course of antibiotics and felt better. Not perfect, but significantly improved. I chalked the events of 2001 up to stress, but in retrospect I am not so sure. I had similar problems in 2002 and 2003 that were also knocked back with some antibiotics, but the pain in my left upper back (and some kind of "presence" there) never did fully clear up. Tests for TB came back negative.

Fast forward to May of this year. I found myself complaining about "my usual pain," as I had started to call it, more and more. I started to wonder if I was even going to be able to make my annual camping trip out in western New York state at the beginning of July, but upon return to California things started to go downhill for me again. This time I was coughing up some strange stuff. Some of it was white and reminded me of dental plaque. In spite of being a dentist, I never had the best oral hygiene so I'm familiar with plaque. The "plaque" I was getting out of my lungs was some nasty stuff.
smelled just like dental floss used after a couple of days without brushing. Yeah, I know I should be better about that, but stay up late and if my wife is already asleep don't always turn the light on and wake her up so I can brush before bed. To help prevent more tooth decay my dad bought me one of those fancy rechargeable electric toothbrushes that really powers away the plaque. It creates a fine aerosol mist of plaque, and I started to wonder if years of using this brush had caused me to breathe in some plaque mist and moved an infection into my lungs. I inquired several physicians about "lung plaque" and most of them had heard of such a thing. One told me he had heard of something like that in people who were exposed to asbestos, though. Search Google didn't turn up any relevant hits on the subject.

By early September 2004, I was spending a good portion of the time I'd normally be working online flat on my back instead. The pain that had started in my left upper back had moved into my left side below the ribs, and my right side just under my armpit, too. As an ex-smoker, worries of lung cancer were starting to consume my thoughts. A close friend of my father's had recently died of that disease, and his initial symptom was also shoulder pain -- they treated him for a presumed pulled muscle for many months while the real problem went undiagnosed. Sometime in October I decided that it was time to pull my head out of the sand and get in to see my usual physician who runs a small clinic in Concord, tell him all of this stuff, and at least try to get cancer ruled out. He ordered chest X-rays, blood work, ran an EKG, and checked all my usual vital signs. I told him about the "lung plaque" and reported feeling weak all the time with no appetite. Being 6'2" and about 145 pounds I knew I didn't want to be losing any weight. He also listened to my chest and like all the doctors I've seen this year thought it sounded mostly clear, like there wasn't anything major going on the X-ray. It was taken on a Thursday and I was told not to expect to hear anything until sometime the next week. Well, the next morning the phone rang and it was my doctor. He told me there was something "suspicious" seen in my left upper lung (right about where the long-standing pain was), and that I needed to get some more X-rays at the local hospital instead of the imaging center I'd gone to before. They weren't going to get me in there until the next Monday.

The next morning I decided that I'd better FedEx some T-shirts to Slackware developer Patrick who needs your help acquiring penicillin and information about the disease Actinomycosis.
my friends at the GUS in Brazil had been waiting for (not knowing how much longer I could procrastinate on that, etc). While I was back I felt a sharp pain in my left side and felt something pop and drain (maybe into the pleura?), and since cancer was on my mind, as well as the fact that this had been going on for too long, I headed straight to the nearest ER hoping I wasn't bleeding internally or something like that. By the time the doctor saw me I was holding onto my left side which seemed to help the pain a bit. He ran a UA (and called it "questionable") and sent me down for a CT scan. No iodine dye -- just a lower abdominal scan to see if I had any kidney stones (and yes, I related as much of this other info as he had time to hear in a busy ER). No stones were found; he wrote me a script for Cipro and some pain medication. I showed up at the hospital the next day (in only slightly better shape) to try to schedule additional X-rays, but they had misplaced the fax the doctor had sent in, and they didn't want to schedule additional images until they had seen the first ones. I never did see those first X-rays and the imaging center requires a 48 hour notice to check out films. It was starting to look like going through this medical center was going to be a slow process, and I wasn't sure I had that kind of time. So, I made the decision to pack up the car and drive back to North Dakota from California. My Dad has been part of the medical community for years there, and knows a lot of people. I figured he would know who I should be seeing, and could help me set something up. A week ago Sunday (Nov. 7) my wife Andrea and I set out to make the drive to Fargo. We made it as far as Monida Pass. This is a mountain pass on the Idaho/Montana border with an elevation of 6820 feet. On the way up the grade I knew it wasn't going to be kind to me. I felt an intense squeezing under my sternum and started to sweat and nearly passed out. I've never previously had any trouble with high elevations and have done hiking and mountain biking at much higher one particular pass. Luckily Andrea was driving at the time! We decided that we would stop at the next fairly large town with a hospital to see what they could do for me. This was Butte, Montana, an old mining town, and home of St. James Hospital. The folks there were wonderful to me. They did some more blood work (finding only a slightly low potassium level), chest X-rays, and a CT with the iodine dye didn't wait long for the dye to circulate because they said the main goal there was to insure I didn't have a pulmonary embolism like that. The doctor and radiologist also told me my lungs looked "slightly inflamed" and to stay on the Cipro, but that I was...
to keel over before making it to Fargo, especially as I’d be losing elevation rapidly upon heading east. They packed the X-rays and CT scans into a big envelope and told me I could borrow it to my doctor in Fargo, and that they see a lot of people come pass with similar problems. So, off we went. I was mostly back to Fargo, but never lost the feeling that someone was my chest pressing on my sternum, and was occasionally short even after getting down to the 1000 foot elevation.

Back in Fargo, I had an appointment with an internal MD on morning. By Wednesday night the pressure under my sternum was bad that it felt like I was having a heart attack, and was taken to an ER (the Slackware 2004 ER tour continues). While I started to feel better, and the pressure was letting up, did not want to be a GOMER in their emergency room. The doctor the next day focused on the possibility of a thyroid or liver and ran some more tests that came back looking ok. He thought from Butte looked "within normal limits". That night I again squeeze (pericardis?) but suffered through it because I didn’t want to go back to the ER. I’ve had at least one strong attack since, along with the sensation of "pop and drain" in all the pain points and under my sternum. The next day (Saturday, to a local clinic with an MD in private practice. This guy is great, and has seen me about a half dozen times since. He that I had signs of serious infection, including a disgusting garlic/sulfur smell you could detect at 50 paces. He put me on levafquinone and metronidazole hoping to have a better chance of covering whatever the responsible bacteria was. Took more X-rays but couldn’t see anything obvious. We discussed getting an echocardiogram to look for pericardius.

Then, I got my Google breakthrough. One of the symptoms I’ve noticed over a year ago was feeling like something hard was in my throat causing me to cough. Maybe 4 times I was able recover was looked like a small (<= 1mm), round, hard granule was light yellow in color. I’m sure I swallowed a bunch of but hadn’t seen too many examples and had not remembered to mention this to any MDs along the way. I googled for "yellow granule" and maybe the third hit mentioned something called Actinomycosis. There it was, a laundry list of the symptoms I’ve been experiencing. Furthermore, the disease is caused by the same bacteria that normally lives in the mouth and in dental
plaque. Infections are most common in the jaw, but sometimes occur in the lungs and spread elsewhere through the body. The hallmark of the disease is the finding of small granules of sulfur. Aha, I thought. Now that I know what this is, I should be able to get some treatment. I tried "sulfur lung granule" on Google instead and had a ton of hits, all highly relevant to the situation I was experiencing. I printed out one of them from the Johns Hopkins Microbiology newsletter and raced back to the clinic to tell Rodney about it. He looked it over and thanked me for doing so much work for him (whatta guy :-), on the basis of what I'd told him felt there was a good chance that we were looking at the answer right there. None of the antibiotics I was on would touch this -- they were all too modern. That was one of the terrible side effects of old antibiotics; they would kill the natural flora in the mouth and GI tract and you have all kinds of problems like fungal and yeast infections as a result. So the newer classes of antibiotics are carefully chosen to avoid killing those types of bacteria, and this was probably caused by Actinomyces, the most common bacteria in the mouth. When found in a lab culture, its presence tends to be discounted as normal. So, what kills this stuff? Good old penicillin. Yup, while everything else in the world became resistant to penicillin and amoxicillin, Actinomyces israelii never did. Rodney had me quit taking the other antibiotics and put me on amoxicillin (even though V-cillin-K 1g qid might have been a better choice). I've been on it for a couple of days and I'm doing a bit better. I don't stink anymore and the palms of my hands have quit sweating. He also gave me five days of prednisone which seems to be lessening the frequency of the chest attacks, although one did get me out of bed at 03:00 last night (and I took the opportunity to start working on this hoping to save myself). Problem is, things are somewhat contained, but still appear to be spreading. I'm getting sudden pressure releases occasionally that seem to be coming from the pleura or pericardium, and this morning had one that seemed to be inside my head. This has me more than a little concerned. From everything I've read about this, it is a really tough thing to treat. Oral penicillin generally does not do it. What is needed is 2 to 6 weeks of IV penicillin G (12 to 24 million units a day), followed by 12 months of V-cillin-K 1g four times a day. Amoxicillin 500mg 3 times a day has me in a holding pattern, but it's probably not going to do the trick. Rodney has no
to directly admit me to a hospital without first sending me to an infectious disease MD there who would have to agree with all of this. I have an appointment on Friday.

There you have it. That's where I am today. If anyone out there is familiar with this and is able to help, please let me know. I'll travel anywhere I have to at this point. I can be reached on my cell phone at (925) 535-9062. Please call only if you can get me some high-dose antibiotic treatment. I have been trying to check email at least once a day at volkerdi@slackware.com and I'll accept whatever you'd like to send me at that address (as usual :-), but if you're contacting me with an offer of help, please add [HELP] to the subject so that I'll be able to find those more easily. Say prayers, knock on wood, whatever. I need help I can get. Anything sent here will be confidential unless you say otherwise, too. I also hope if I'm off the job for a couple more weeks that the Slackware community will still support me when I can return to the job, which I'm really itching to do ASAP (I'm not looking for donations though). This experience has changed my perspective on a lot of things, and I think the future will be different (and better).

Oh, there's this blood test result which I should also mention. While almost everything looks normal there, the following white cell counts are (barely) out of the normal range:

- Neutrophils 79 (high) NormalRange = 40-75
- Lymphocytes 16 (low) = 20-45
- Absolute Eosinophil 0.00 (low) = 0.015-0.500

BTW, my login quote tonight was "Snow and adolescence are the problems that disappear if you ignore them long enough." heh.

Thanks for listening.

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Patrick J. Volkerding

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http://slackware.osuosl.org/slackware-current/PAT-NEEDS-YOUR-HELP.txt

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